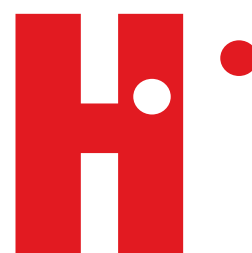


**16th Australian & New Zealand
Haemophilia Conference**

20 - 22 October 2011

Health and wellbeing – the decade ahead



Conference Handbook and Abstracts



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NATIONAL PATRON - MESSAGE

The Rt Hon Sir Ninian Stephen KG, AK, GCMG, GCVO, KBE



4 Treasury Place
Melbourne 3002
Victoria Australia

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Facsimile: +61 3 9650 0270
Email: ninian.stephen@pmc.gov.au

Welcome to the 16th Australian & New Zealand Haemophilia Conference hosted by Haemophilia Foundation Australia in Sydney.

As the bleeding disorders' communities of Australia and New Zealand come together for the 2011 conference I hope you will enjoy the conference sessions and the time to meet and share together. The conference theme of "health and wellbeing" offers something for everyone in attendance.

I am delighted that Australia will host the World Federation of Hemophilia Congress in Melbourne in 2014 and look forward to welcoming you to Melbourne for our next gathering!



Sir Ninian Stephen
National Patron
Haemophilia Foundation Australia

WELCOME

We welcome you to the 16th Australian & New Zealand Haemophilia Conference in Brisbane.

People with bleeding disorders and their families and carers, health professionals, policy makers, industry representatives and many other stakeholders will have an opportunity to share information and knowledge about the current issues for treatment and care and to participate in discussions about some of the important emerging issues for the future.

We sincerely thank the Program Committee for working so hard over recent months to bring what we hope will be a very exciting meeting to you. The hard work and personal and professional commitment of all those who have participated is greatly appreciated.

We hope you enjoy the conference, and find it a stimulating and informative meeting.

Gavin Finkelstein
President
Haemophilia Foundation Australia

Deon York
President
Haemophilia Foundation of New Zealand

Dr Julie Curtin
Chair
Conference Program Committee

Program Committee

Dr Julie Curtin (Chair)	Australian Haemophilia Centre Directors' Organisation (AHCDO)
Belinda Burnett	Executive Officer, Haemophilia Foundation of New Zealand
Sharon Caris	Executive Director, Haemophilia Foundation Australia
Alex Coombs	Australia/NZ Haemophilia Social Workers' & Counsellors' Group
Nicola Hamilton	Australian and NZ Physiotherapy Haemophilia Group
Sharon Hawkins	Australia/NZ Haemophilia Social Workers' & Counsellors' Group
Leonie Mudge	Australia/NZ Haemophilia Social Workers' & Counsellors' Group
Kate Lenthén	Australia/NZ Haemophilia Social Workers' & Counsellors' Group
Tommy Leung	Community Representative
Stephen Matthews	Australian Haemophilia Nurses' Group
Colleen McKay	Haemophilia Foundation of New Zealand
Suzanne O'Callaghan	Policy Officer, Haemophilia Foundation Australia
Abi Polus	Australian and NZ Physiotherapy Haemophilia Group
Wendy Poulsen	Australian and NZ Physiotherapy Haemophilia Group
Dr Susan Russell	Australian Haemophilia Centre Directors' Organisation
Dr Megan Sarson	AHCDO Project Officer
Robyn Shoemark	Australian Haemophilia Nurses' Group

GENERAL INFORMATION

Conference Organisers

Haemophilia Foundation Australia
1624 High Street, Glen Iris VIC 3146
P: 03 9885 7800 F: 03 9885 1800
E: hfaust@haemophilia.org.au W: www.haemophilia.org.au

Venue

The Novotel Sydney Olympic Park
Olympic Blvd, Sydney Olympic Park
Homebush
P: 02 8762 1111

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/Pagers

As a courtesy to delegates and speakers, please switch off, or set your mobile phones and pagers 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 staff at the Registration and Information Desk.

Business Centre

There is no business centre at the Novotel – internet is available in the reception area free of charge for 20mins. If you require printing or other services, please see the secretariat office.

Registration and Information Desk

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

Thursday 20 October 17:00 - 19:30
Friday 21 October 07:30 - 17:30
Saturday 22 October 08:00 - 15:30

Haemophilia Treatment

There is no treatment room at the Conference venue. Treatment services for people with bleeding disorders are available at:

Royal Prince Alfred Hospital
Haemophilia Centre (Adults)
Building 77, Level 5 Missenden Road Camperdown NSW 2050
Telephone 02 9515 7013
Emergency 02 9515 6111

The Children's Hospital
Cnr Hawkesbury Rd & Hainsworth St Westmead NSW 2145
Telephone 02 9845 0839
Emergency 02 9845 0000 and page haematologist on call

Sydney Children's Hospital
Centre for Children's Cancer & Blood Disorders
High St Randwick NSW 2031
Telephone 02 9382 1690 Doctor
02 9382 1240 Nurse
After hours 02 9382 1111 and page haematologist on call

Childcare

Childcare will not be available and children are not permitted in Conference sessions.

SOCIAL PROGRAM

Thursday 20 October

Welcome & Exhibition Opening

18:30 – 19:30

Freshwater Room 1

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

Youth Meet and Greet

19:30 til late

Boulevard Bar

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

Friday 9 October

Remembrance Service

18:15 – 18:45

Terrace

The Remembrance Service is a time to remember friends and family, and the people we have cared for in our community, who have died. The service is non-religious and everyone is welcome.

Conference Dinner

19:00 til late

Freshwater 2 & 3

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

Saturday 22 October

Men's Breakfast

07:30 – 08:45

Women's Breakfast

07:30 – 08:45

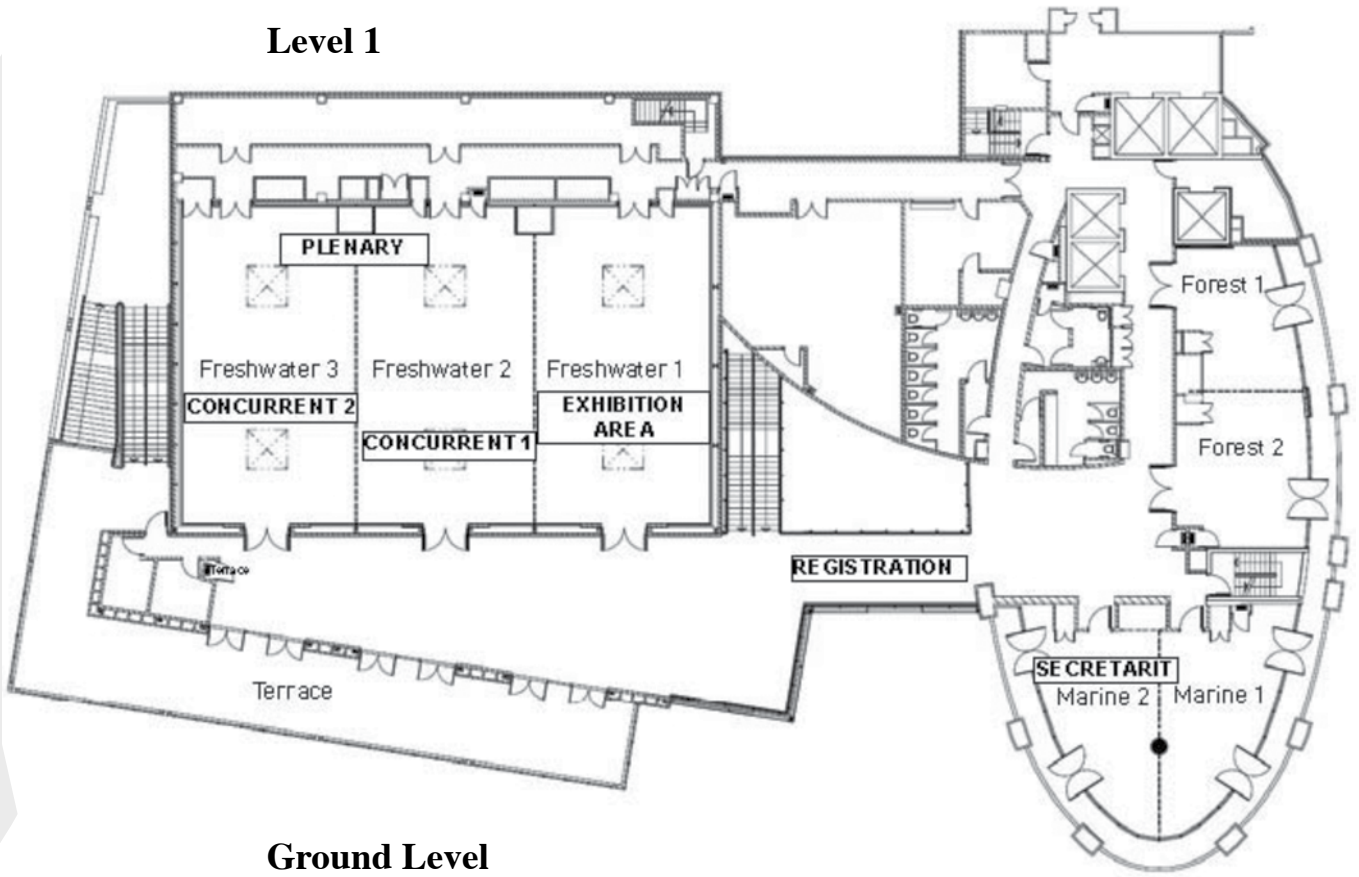
Tickets to both the Men's and Women's breakfast must have been pre-purchased, no tickets are available during the conference.

Australian & New Zealand Inhibitors Workshop

The Australian & New Zealand Inhibitors Workshop will be held on 22-24 October is supported by an education grant to HFA from Novo Nordisk. This grant has enabled HFA and HFNZ to develop a specialized workshop for people living with inhibitors and their carers.

CONFERENCE VENUE MAP

Level 1



Ground Level



SPONSOR AND EXHIBITION DIRECTORY

Baxter Healthcare Pty Ltd

Contact: Danielle Byers
PO Box 88, Toongabbie, NSW 2146
P: 02 9848 1111

Bayer Australia Limited

Contact: Wendy Thomas
875 Pacific Highway, Pymble, NSW, 2073
P: 02 9391 6000

Biogen Idec

Contact: Sally McAlister
133 Boston Post Rd, Bldg 15-123 Weston, MA 02493
P: 0011 +1781 464-4238
Email: Sally.McAlister@biogenidec.com

CSL Limited, Bioplasma Division

Contact: Dr Christopher Fry
189-209 Camp Rd, Broadmeadows, VIC 3047
P: 1800 063 892

Novo Nordisk Pharmaceuticals Pty Ltd

Contact: Patricia Fiskén
Level 3, 21 Solent Circuit, Baulkham Hills, NSW 2153
P: 1800 668 626

Pfizer Australia

Australia Contact: Monica Collins
New Zealand Contact: Warwick Jeffery
38-42 Wharf Road, West Ryde NSW 2114
P: 02 9850 3333

Haemophilia Foundation Australia and state/territory Haemophilia Foundations

Contact: Sharon Caris
1624 High Street, Glen Iris, VIC 3146
P: 03 9885 7800 M: 0410 419 914
Freecall: 1800 807 173

Medicines Australia Code of Conduct

HFA supports the regulatory framework for prescription medicines in Australia and all activities will comply with the Medicines Australia Code of Conduct.

CONFERENCE PROGRAM

THURSDAY 20 OCTOBER 2011

1830-1930	Welcome and Exhibition Opening @ The Novotel – Freshwater Room 1
1930 til late	Youth Meet and Greet @ The Novotel - Boulevard Bar

FRIDAY 21 OCTOBER 2011

0900	Official Welcome Gavin Finkelstein, HFA President and Deon York, HFNZ President Room: Freshwater Room 2&3		
0910- 1030	Plenary 1 How a happier body can lead to a happier mind - Anna Louise Bouvier Room: Freshwater Room 2&3		
1030-1100	MORNING TEA		
1100-1230	Concurrent 1 Keeping the body in tune - children Room: Freshwater 2	Concurrent 2 Staying on your feet – a session for adults of all ages Room: Freshwater 3	Concurrent 3 Von Willebrand Disorder Room: Parklands
	Chair: Wendy Poulsen Managing diet – dealing with fussy eaters – Dr Jacqui Dalby-Payne Risk of bleeds associated with physical activity in children with haemophilia - Dr Carolyn Broderick Personal Experience – Chris Gordon Questions	Chair: Dr Huyen Tran Saving the Ankle Joint – Dr Sanjeev Gupta Haemophiliac joints in children: can we preserve them from damage? - A/Prof Prudence Manners & Dr Ann Powell Staying on your feet – a session for adults of all ages - Emma Paterson	Chair: Dr Susan Russell A personal story of a family affected by VWD – Manal Awad VWD – clinical update on treatment and care – Dr Mandy Davis Diagnosis and classification of VWD – Dr Emmanuel Favalaro Questions
1230-1330	LUNCH		
1330-1500	Concurrent 1 Keeping the mind and body in tune - adults Room: Freshwater 2	Concurrent 2 Women’s health and reproduction Room: Freshwater 3	Concurrent 3 Transitions: becoming an adult Room: Parklands
	Chair: Andrew Atkins Obesity/weight management: clinical issues - TBC Personal experiences: Andrew Selvaggi and Zev Fishman will share their inspiring stories of overcoming some of the complications of haemophilia Creating flourishing lives: putting positive psychology into practice – Nicola Gates Discussion	Chair: Belinda Burnett IVF and embryo diagnosis – Dr Kristi Jones Managing menorrhagia - Dr Claire McLintock HFNZ Women’s Program – Lynne Campbell	Chair: Maureen Spilsbury “Transitioning in Queensland: From Teddy Bears to Apprenticeships!” – Maureen Spilsbury & Dr Desdemona Chong WA Transition program Presented by Haemophilia Counsellor – Sharon Hawkins and William Oversby A panel of youth and young adults will discuss their experiences
1500-1530	AFTERNOON TEA		
1530-1700	Plenary 2 Ageing Room: Freshwater Room 2&3		
	Chair: Zev Fishman Haemophilia and Ageing – Dr Mike Makris Followed by multidisciplinary panel: Leonie Mudge (Social Worker), Ian d’Young (Physiotherapist), Stephen Mathews (Nurse)		
1815-1845	Remembrance Service @ The Novotel - Terrace		
1900 til late	Conference Dinner (\$30 per person, tickets must be pre-purchased) @ The Novotel – Freshwater 2 & 3		

Conference Program

SATURDAY 22 OCTOBER 2011

0730-0845	Men's Breakfast (\$25 per person, tickets must be pre-purchased)		
0730-0845	Women's Breakfast (\$25 per person, tickets must be pre-purchased)		
0900-1030	Plenary 3 Treatment challenges Room: Freshwater Room 2&3 Chair: Dr Scott Dunkley		
	Safety of current products used to treat inherited bleeding disorders – Dr Mike Makris Current and emerging challenges, risk factors for inhibitor development – Dr Julie Curtin Update from the AHCDO Tolerisation Advisory Committee – Dr Chris Barnes Inhibitors in mild haemophilia – Dr Simon McRae A personal experience of tolerisation – Hamish Robinson Questions		
1030-1100	MORNING TEA		
1100-1230	Concurrent 1 Men's Business Room: Freshwater 2 Chair: Sharon Hawkins Facilitator: Greg Millan	Concurrent 2 The challenges of prophylaxis Room: Freshwater 3 Chair: Ian d'Young	Concurrent 3 The rarer bleeding disorders Room: Parklands Chair: Grainne Dunn
	What's normal? – across the lifespan - Greg Millan Enjoying your sex life: Issues and solutions for men with physical impairment – Dr Tinashe Dune Panel – Q&A Haemophilia physiotherapist – Cameron Cramey Haemophilia nurse – Clare Waite Haemophilia Counsellor - Sharon Hawkins BBV's , and body image - Dr Roger Garsia	Clinical update on prophylaxis – Dr Alessandro Gringeri Delivery of Prophylactic Factor to Children with Severe Haemophilia: the challenge of venous access – Dr Susan Russell & Robyn Shoemark Joint health for children and adolescents: Prophylaxis is not the only answer – Ian d'Young	A personal story by a mother of a child with severe factor XI deficiency – Nadine Penn Nursing perspectives – 3 nurses will present snapshots of their experiences of looking after patients with rare bleeding disorders and the nursing issues that arise: Acquired haemophilia - Andrew Atkins Afibrinogenaemia - Olivia Hollingdrake Glanzmann's- Penny McCarthy Factor X deficiency - Dr James Price Platelet function disorders – Dr Tim Brighton Discussion
1230-1330	LUNCH		
1330-1500	Concurrent 1 Living with hepatitis C and/or HIV co-infection Room: Freshwater 2 Chair: Megan Walsh	Concurrent 2 Caring for parents and carers Room: Freshwater 3 Chair: Dr Desdemona Chong	Concurrent 3 Communication and Social media Room: Parklands Chair: Jonathan Spencer
	From a patient's perspective - Luke Ahern Medical update on HIV co-infection including reproduction for HIV discordant couples – Dr Roger Garsia Update on hepatitis C and treatment – A/Prof Simone Strasser Managing symptoms and liver health – A/Prof Frances Tenison	Taming the Stress Dragon - Dr Desdemona Chong Empowering Parents! PEP in Australia - Anne Jackson Re-PEP in New Zealand – an opportunity to review, re-visit, reflect and refresh - Colleen McKay The benefits from a Mother's perspective - Lynley Scott The benefits from a Father's perspective - Richard Scott Caring for Carers across the spectrum - Elena Katrakis	Social networking – community perspectives and issues to consider for community organisations – Suzanne O'Callaghan Ethics & impact of social networking for health professionals/doctors – TBC Privacy and reputation management in the digital space – Melissa Sevil Panel discussion
1500-1530	AFTERNOON TEA		
1530-1650	Plenary 4 Treatment and care – now and the future Room: Freshwater Room 2&3 Chair: Geoff Simon		
	What are some of the issues? – Geoff Simon Expectations from a community perspective – Deon York Optimising supply and demand for clotting factors – Stephanie Gunn The future of haemophilia care – a personal view - Dr Mike Makris Discussion		
1650-1700	Closing Gavin Finkelstein, HFA President and Deon York, HFNZ President		

POSTER DISPLAY

The poster display is in the main foyer area. All posters will be displayed for the duration of the conference.

POSTER 1

Name: Claire Bell

Institution/Organisation: Haemophilia Centre of WA, Royal Perth Hospital

Title of Abstract: Hepatitis C infection in adults attending the Haemophilia Centre of Western Australia: Current infection status and impact of hepatitis C

Background:

Hepatitis C virus (HCV) has affected those with inherited bleeding disorders for over 20 years. With increasing age and duration of infection being key factors in the development of fibrosis and cirrhosis, the aim of this audit was to gain a snapshot into our population of patients with inherited bleeding disorders affected by HCV.

Methods:

A retrospective audit was conducted on patients with inherited bleeding disorders who demonstrated a positive antibody to HCV. Data was retrieved from patient case notes and the ABDR.

Results:

There are currently 115 patients that are HCV antibody positive. 55% are now PCR negative, leaving 41 % PCR positive and 4% currently receiving treatment.

Of the PCR negative population, 46% are spontaneous resolvers. The remaining 54% had successful treatment outcomes, with 65% achieving a SVR with Peg-IFN and ribavirin. Of those that achieved a SVR, 20% underwent more than one treatment regimen in order to do so, 71% of which did so with Peg-IFN and ribavirin.

The PCR positive population is predominately male (87%) with an average age of 42.8 years. The majority of patients have haemophilia A (68%). It is made up of those who have undergone treatment and were either non-responders or relapsed (43%) and those who have not attempted treatment (57%). Of those who have received treatment, 35% have experienced two or more rounds of treatment. 55% of the PCR positive patients did not achieved a SVR with Peg-IFN and ribavirin. The majority are genotype 1 (57%), however 21% have an undiagnosed genotype. In 2010/11 only 30% had a documented abdominal ultrasound, 57% of which showed some abnormality including cirrhosis (50%). 1 patient had had a fibroscan and only 21% of patients had had a hepscore performed, compared to 45% having had an AFP performed. The most common blood test performed were ALT and AST (72%).

Of the HCV/HIV co-infected population 14% have achieved a SVR with a further 14% having poor treatment outcomes. 72% have not attempted treatment.

There has been two liver transplants conducted on patients with advanced liver disease related to HCV and one death resulting from HCC.

Discussion:

There are still a significant number of patients currently infected with HCV, a sizable portion of which have had limited monitoring for fibrosis/cirrhosis. It is essential that this patient group are monitored appropriately and provided with information regarding treatment options.

POSTER 2

Name: Chantel Lauzon

Institution/Organisation: Haemophilia Foundation of New Zealand Inc.

Title of Abstract: The Extra Burden: Outcomes of the 2010 People with Haemophilia and Hepatitis C Survey

Over a third of the people with bleeding disorders (PWBD) exposed to hepatitis C in blood products in New Zealand continue to live with chronic hepatitis C (HCV) and the additional toll this has on their health and well-being. To understand the impact of HCV in this community a self-completed survey was circulated to 61 people PWBD and chronic HCV currently living in New Zealand. Respondents were asked about demographic information, employment, treatment for hepatitis C, liver health, HCV education and support, discrimination, their general health, activities and psycho-social functioning. In total 32 surveys (52%) were completed and returned. The majority of respondents were aged over 61 years (50%) and less than a third were in full-time employment (28%). Over half (53%) of the respondents had previously attempted interferon therapy and 53% had undergone a FibroScan®. Nine (32%) of respondents indicated they had cirrhosis. Most participants felt they were well informed about HCV. Only a third of respondents felt they had been discriminated against due to their viral status. In general, the majority of participants (55%) reported feeling good or very good, although most reported having severe physical limitations, especially in relation to vigorous activity (64%). While PWBD are often physically impacted by joint arthropathy, most are able to go about daily activities. The survey showed that the majority found daily tasks harder to complete, both because of pain (56% at least some of the time), and also loss of energy (75% at least some of the time). Apathy affected over three-quarters of respondents (76%). Although most reported making positive lifestyles choices to support their liver health, many respondents indicated that HCV casts a shadow on their lives and that they worry about the long-term effects of HCV infection.

POSTER 3

Name: Suzanne O'Callaghan

Co-authors: Sharon Caris

Institution/Organisation: Haemophilia Foundation Australia

Title of Abstract: The Wellbeing Weekend: learning to live well with hepatitis C for people with bleeding disorders

Haemophilia Foundation Australia (HFA)'s recent needs assessment of the bleeding disorders community affected by hepatitis C highlighted individuals' lack of knowledge about hepatitis C, concerns about disclosure, social isolation, overload with health conditions and need for support. One community recommendation was to develop an educational "Wellbeing Weekend" for people with bleeding disorders and hepatitis C and their partner/support person, with a focus on wellbeing and hepatitis C. This should include enjoyable activities and unstructured time.

The program for the Weekend was developed by a group which included members of the affected community, haemophilia organisation representatives, community educators and health professionals. The Weekend offered a range of practical activities to enable participants to learn more about hepatitis C and wellbeing and try out various strategies to improve wellbeing, including fun and creative approaches, and incorporated time for talking together informally, resting, taking medications, walking and having a massage.

The Wellbeing Weekend was piloted with 17 participants (11 men with bleeding disorders and 6 partners/support people). It was led by an educator and a haemophilia counsellor. In the evaluation, participants rated sessions very highly and felt that the holistic focus on issues specific to their health condition was helpful. They enjoyed the opportunity to meet each other and share experiences while learning in a safe and confidential environment. They felt the Weekend gave them the tools to "make a difference" to their health and many continued to use the strategies afterwards.

As a result of the successful pilot, HFA has developed a Wellbeing Weekend Toolkit to enable other haemophilia organisations to conduct their own Weekends.

POSTER 4

Name: Dr Nyree Cole and Ms Judy Gilmour

Co-authors: Dr Lochie Teague, Dr Peter Bradbeer, Dr Paul Ockelford

Institution/Organisation: Auckland District Health Board

Title of Abstract: The Experience of Portacath Use in Children Managed by the Auckland Haemophilia Centre over the last 10 years

Topic Area:

To assess the morbidity associated with portacath use in children with severe bleeding disorders managed by the Auckland Haemophilia Centre in the last 10 years.

Outline and description of topic/content of presentation/project:

11 children with a total of 28 ports were managed by the Auckland Haemophilia Comprehensive Care centre between April 2001 and April 2011. Indication for port placement included primary and secondary prophylaxis, induction of immune tolerance, prophylactic therapy post intracranial hemorrhage and poor venous access. The age range at first port placement was between 5 months and 4 years.

Infection, as identified by positive catheter blood culture, was the most common complication. Out of 28 ports, 23 had proven infection. Organisms most frequently isolated were the Staphylococcus species but Pseudomonas aeruginosa and Candida albicans were also isolated. All infections were treated with IV anti-microbials and required prolonged hospital stays. Ten of these antimicrobial courses were successful but thirteen infections necessitated port removal. In keeping with the current literature, infection was the most common reason for removal.

Other reasons for removal were blockage (3), displacement (2), port hub leaking (1) controlling haemostasis (1) and catheter breakage (1). 2 of these ports had more than one complication. Only 2 ports were removed electively.

Conclusions/outcomes:

The use of portacaths in children with a severe bleeding disorder is associated with significant morbidity however, for a group of children, prophylaxis or immune tolerance would be impossible without central venous access. The decision to insert one of these devices needs very careful consideration. There must also be appropriate parent/carer education on the safe management of port access and early recognition of complications.

POSTER 5

Name: Janine Furnedged

Co-authors: Dr Fiona Newall, Dr Chris Barnes, Professor Paul Monagle

Institution/Organisation: Royal Children's Hospital, Melbourne

Title of Abstract: I don't want to hurt him – parents' experiences of learning to administer clotting factor to their child

Haemophilia is a potentially life threatening bleeding disorder for which treatment is administered intravenously. Infusaports are commonly used to establish reliable intravenous access in young children and most families learn to access their child's infusaport to give treatment at home. Provision of education is critical to ensure families can safely carry out infusaport care however few studies have explored the provision of infusaport education to parents. There is a clear need to study the learning needs of this population to inform the process for teaching this complex and often confronting task. The purpose of this study was to explore the experiences and education needs of parents learning to use an infusaport to administer clotting factor to their child with hemophilia. A qualitative approach was undertaken using focus groups to gather information. Fifteen parents of children who attend the Hemophilia Centre at The Royal Children's Hospital, Melbourne attended two focus groups. Data was transcribed verbatim and analysed thematically. Parents described distress and trauma in dealing with the diagnosis and treatment of their child's haemophilia. It was within this background context that parents began the infusaport education process. Four major themes emerged from the data: dealing with fear and anxiety; a supportive learning environment; establishing a ritual; and empowerment and liberation. Parents identified a supportive learning environment as their critical need rather than a specific learning process. In addition the concept of ritual emerged both as a mechanism for increasing the child's comfort with the procedure and as a valuable learning tool for their parents. This study highlights the importance of consulting consumers in order to understand their experience of illness and their educational needs. Patient and family education programs should not be limited to the provision of information but must establish and incorporate the needs of the learner.

POSTER 6

Name: Julia Ekert

Co-authors: Janine Furmedge, Dr Chris Barnes

Institution/Organisation: Royal Children's Hospital, Melbourne

Title of Abstract: Recording Home Usage of Clotting Factors-Asking patients and parents what they think

Outline:

Comprehensive patient recording of clotting factor usage is important. Finding an effective tool to record home use Clotting Factor Concentrate (CFC) usage however has been difficult. Recording tools have, in the past, been created without widespread stakeholder engagement; uptake of recording tools has therefore been sub-optimal. To the best of our knowledge, haemophilia patients and parents have not been approached to design a recording tool that meets the needs of patient and families and that will lead to broader uptake of recording programs.

Method:

Patient/parent questionnaires were sent to all families who participate in the home therapy program. Data was collected on the following to guide in the development of a new recording tool;

1. How often do you record home therapy CFC
2. What methods are used to record home therapy CFC
3. Who Records it
4. How important do they think recording home therapy CFC is
5. What things make it hard to record home therapy CFC
6. If we were to design a new recording tool what things are important to you.

Results:

Sixty families were identified with 30 replies received. Of these 22 recorded CFC use for all treatments and they did not find the recording process difficult. Families felt they benefited from recording as it was a way of keeping track of their child's treatment regimen. There were many comments on the routines and nuances of recording CFC usage which will be useful information for designing a new recording tool. As part of the questionnaire we also asked families if they would be happy to participate in a follow up interview to explore themes raised in the questionnaire more thoroughly. These interviews will form the second part of the project and will further investigate the practices of home recording and explore what families feel about recording and sending data into their HTC.

Conclusion:

Engaging families and patients is critical to secure information on recording clotting factor concentrate. The information from questionnaires and interviews will inform the design of a new tool for recording clotting factor usage and lead to broader uptake of clotting factor recording.

POSTER 7

Name: Tara Skye Mooney

Co-authors: Dr Esben Strodl, Dr Simon Brown

Institution/Organisation: Tara Mooney – Child and Youth Mental Health Service, Children’s Health Services District, Brisbane, Queensland, Australia; Dr Esben Strodl – School of Psychology and Counselling, Queensland University of Technology, Brisbane, Queensland, Australia; Dr Simon Brown – Royal Children’s Hospital, Brisbane, Queensland, Australia

Title of Abstract: Mothers of Children with Haemophilia: An Exploration of Their Experiences

Aim:

There continues to be poor treatment adherence in children and adolescents with haemophilia, despite obvious treatment benefits. Parents are responsible for administering treatment up until, and frequently throughout, adolescence. Therefore, they play a fundamental role in treatment adherence.

Paediatric haemophilia literature has, until now, been predominantly quantitative and focused largely on the quality of life of patients and parents. The few studies that have investigated parents’ experiences of having a child with hemophilia have been conducted predominantly in the United Kingdom. We aimed to qualitatively explore experiences of parents with children who have severe hemophilia A, in the hope of identifying influences on treatment adherence and nonadherence.

Method:

Seven biological mothers, of children (aged between 2 and 16 years) with severe hemophilia A on primary prophylaxis, were interviewed. The data were analyzed using interpretative phenomenological analysis (IPA). IPA involves detailed examination of participants’ lived experience. Behaviour is, in part, influenced by an individual’s beliefs and experience. As such, undertaking IPA will help to identify possible influences on parents’ behaviour and thus their approach to their child(ren)’s treatment.

Result:

Six main themes were extracted: parental responsibility to protect, acceptance, appreciation, self-efficacy, this is dangerous and others don’t get it, and treatment importance versus practicality.

Conclusion:

Poor adherence in children with hemophilia is a significant medical problem. Possible interventions for improving adherence include: increasing parents’ acceptance, appreciation, self-efficacy, and time management; and challenging their perception of danger and trustworthiness of others. Further research is required in order to assess whether improvements in any of these areas can result in improvements in adherence behaviours in children with hemophilia.

POSTER 8

Name: Dr John Rowell, Dr Chris Barnes, Sharon Caris, Stephanie Gunn, Chris Hogan, Barbara Herden

Institution/Organisation: Dr Rowell and Dr Barnes, Australian Haemophilia Centre Directors' Organisation; Sharon Caris, Haemophilia Foundation Australia; Stephanie Gunn, Chris Hogan, Barbara Herden, National Blood Authority

Title of Abstract: Australian Bleeding Disorders Registry – A Collaborative Approach

Aim:

The Australian Bleeding Disorders Registry (ABDR) was first established in 1988. The aims of the ABDR were to provide a clinical tool for improved management and national demographics for People with Bleeding Disorders (PWBD).

Method:

Through collaboration with clinicians, patients and governments, the redeveloped Registry was deployed in 2008 to provide, for the first time in Australia, a national view on the size, nature and complexity of the clinical treatment requirements of PWBD. A Steering Committee was established comprising individuals from the Australian Haemophilia Centre Directors' Organisation (AHCDO), the National Blood Authority (NBA) and the Haemophilia Foundation of Australia (HFA). This Committee ensured extensive consultation with every speciality involved in the care of patients including AHCDO, the Australian Haemophilia Nurses' Group, the Australia New Zealand Haemophilia Social Workers/Counsellors' Group and the Australian and New Zealand Physiotherapy Haemophilia Group.

Data base managers (DBM), funded by the NBA, are responsible for data input and maintenance. DBMs meet regularly to create and maintain data dictionaries, trouble shoot, produce reports for the Haemophilia Treatment Centre and provide training for the newly appointed DBMs.

Result:

The ABDR Annual Report 2009-10, released early in 2011, represented the first analysis of the ABDR data since the redevelopment in 2008. This allowed comparison of data input by jurisdiction and product. The results were tempered by some data quality issues such as incomplete records and some product use not recorded. Also, inconsistent definitions appear to be used for particular fields and others require further development to ensure a 'standardised' collection such as a list of values for 'purpose of treatment' for clinical consistency.

Conclusion:

The release of the ABDR Annual Report provides valuable insight into supply challenges and bleeding disorder demographics in Australia. However, it is clear that further development in data quality and consistency is required.

No conflict of interest to disclose

Glossary	ABDR	Australian Bleeding Disorders Registry
	AHCDO	Australian Haemophilia Centre Directors' Organisation
	DBM	Data Base Managers
	HFA	Haemophilia Foundation Australia
	PWBD	People with Bleeding Disorders

POSTER 9

Name: Beryl Zeissink

Co-authors: Olivia Hollingdrake

Institution/Organisation: Queensland Haemophilia Centre,
Royal Brisbane & Women's Hospital

Title of Abstract: Journal Club – keeping up with the evidence

A monthly journal club was commenced at the Queensland Haemophilia Centre, involving staff from both the Royal Brisbane & Women's and Royal Children's Hospital in 2006. Within our haemophilia setting, journal club involves critical analysis of haemophilia or other health related journal articles. This has involved regular attendance and participation by members of the multidisciplinary team, medical, nursing, social work / psychology and physiotherapy staff members.

Journal club provides an opportunity to stay “connected” with relevant research and literature. Journal club articles can be tailored to current work being undertaken by the haemophilia centre, for example dealing with changes, specific patient/family challenges or new advances in technology.

Other benefits have included:

- An additional opportunity for new staff to acquire basic haemophilia knowledge
- Integrating and understanding new information within the haemophilia arena
- Insight into the roles of other multidisciplinary health professionals
- Looking at challenges/concepts from a multidisciplinary perspective and subsequently reflecting on how we practice or changes we can make to our practice.
- Occasions to network with colleagues from both hospitals

Health professionals are also under increasing expectation to demonstrate professional development and education. Journal club is a method that contributes to reflection of self-directed learning.

Journal Club is usually a monthly event and staff members take it in turn to select an article for review. The advantages of this are that individuals have an opportunity to research an area of interest to share with the group. A challenge for the journal club model can be that busy workloads and clinical issues become a priority. Care also needs to be taken re the environment in which it is held. There are benefits to meeting in a relaxed environment such as the café; however noise and privacy issues must be taken into account.

We find the journal club, a useful method of keeping up to date with current advances in haemophilia management and support.

POSTER 10

Name: P Fogarty (HFA), P Isarangkura (NHFT), J Spencer (HFA), M Suwannuraks (NHFT)

Institution/Organisation: Haemophilia Foundation Australia (HFA), National Hemophilia Foundation of Thailand (NHFT)

Title of Abstract: Collaboration through Twinning

The Poster will describe the 5 year twinning partnership between Haemophilia Foundation Australia (HFA), National Hemophilia Foundation of Thailand (NHFT), Thai Patient's Club (TPC), including the 2010 Bangkok Workshop and outreach visit in regional Thailand.

National Member Organisation (NMO) twinning partnerships benefit both the emerging NMO and the experienced NMO in the relationship. A partnership between National Hemophilia Foundation of Thailand (NHFT), Thai Patient's Club (TPC) and Haemophilia Foundation Australia (HFA) has strengthened the patient activities of each organisation by improving communication, providing new tools for reviewing policies and procedures, identifying leaders and building leadership skills, and increasing the confidence of each side of the partnership to represent its members.

Since WFH first provided funding to the organisations in 2006, the collaboration and friendship between the organisations has lead to successful capacity building workshops, and visits of members between Thailand and Australia to develop skills in planning, set objectives and improve capacity to support volunteers to undertake outreach. The outreach in Thailand and other projects undertaken by WFH and NHFT with support from regional outreach volunteers from TPC identified new patients for the patient registry, which strengthened the evidence for increased government funding for the care and treatment for people with haemophilia in Thailand.

In each organisation leaders have been identified to participate in the twinning visits and workshops. Exposure to their twin organisation's way of operating and the exchange of ideas that took place in formal visits, presentations and workshops, observation and informal discussion has enabled individuals to reflect on their own and their organisation's practices, understand the strengths of each approach and communicate this to their own community.

Twinning provides a positive experience for partners and with effective collaboration and a shared commitment to work through communication and cultural differences, successful and sustainable outcomes can be achieved.

POSTER 11

Name: Dr Scott Dunkley

Co-authors: Lian Zhao, Geoff Kershaw, Elaine Uhr

Institution/Organisation: RPAH Sydney

Title of Abstract: Effect of FEIBA on platelet aggregation and activation in severe haemophilia patients with inhibitors

Factor eight inhibitory bypassing agent (FEIBA) is used as a therapeutic option in haemophilia patients who have developed inhibitors. The measurement of thrombin generation has been applied to monitor the efficacy of FEIBA. However a major concern about the clinical use of FEIBA is whether or not an increase in thrombin activity causes subsequent platelet activation.

We evaluate the effects of FEIBA on platelet and leucocyte activity, a concomitant measurement of thrombin generation was also made.

Initially an in vitro study was conducted to evaluate the effects of FEIBA on platelet and leucocyte activity by using peripheral blood from normal volunteers. The measurement was made using flow cytometry. We then performed an ex vivo study looking at the effect of FEIBA on the above parameters in 2 haemophiliacs with high titre inhibitors. A parallel study was also carried out ex vivo to evaluate thrombin generation using a thrombinoscope.

FEIBA did not cause platelet and leucocyte activation in either the in vitro or ex vivo studies but showed a predictable increase in thrombin generation.

Our study is the first to address the effect of FEIBA on platelet and leucocyte function. We found no evidence of 'systemic' platelet activation. The findings suggest that whilst FEIBA improves global haemostasis, platelet activation is likely to be contained to the site of injury and systemic platelet activation, a previously feared consequence of FEIBA infusion that that may have contributed to thrombotic risk is absent.

POSTER 12

Name: Elizabeth J Hitchings

Institution/Organisation: Dental and Oral Health Department, Capital and Coast District Health Board, Wellington, New Zealand

Title of Abstract: Oral health status of individuals with haemophilia.
A review of the literature.

This poster reviews the available evidence on the oral health of individuals with haemophilia. Good oral health is important for general wellbeing for all people, but is more important for those with haemophilia to avoid the bleeding associated with dental treatment.

A comprehensive literature search was undertaken to find studies where participants had haemophilia, and had their oral health described by a measure of prevalence, severity or incidence of an oral condition or state.

Twelve studies, all cross-sectional in design, were found to meet these criteria. Aspects of caries, gingival inflammation, periodontal attachment loss, enamel defects (including fluorosis), malocclusion, temporomandibular joint disorders and oral health-related quality of life were described in those papers. Eight papers compared the study sample with a comparison (“control”) sample.

Dental caries (decay) prevalence ranged from 27 – 94% and the severity of dental caries (measured on a DMFT scale) ranged from 0.5 – 18.

Generally, individuals with haemophilia were found to have worse oral health than controls unless they were part of an oral health programme. However, the quality of the papers was variable and their heterogeneous nature makes comparison of their findings difficult.

The oral health of individuals with haemophilia is likely to be influenced by a complicated interaction of government policies, availability of care and personal prejudices. Better-quality research on the oral health of individuals with haemophilia and their barriers to oral healthcare is needed.

POSTER 13

Name: Emma Paterson

Institution/Organisation: Royal Brisbane and Women's Hospital,

Title of Abstract: RICE and arthritic joints in haemophilia

As a clinician I had noticed a trend with patients with more advanced haemophiliac arthropathy reporting that they had experienced discomfort or difficulty with RICE (Rest Ice Compression and Elevation) for acute bleeds. I also had frequent reports they had ceased using RICE on these joints during acute bleeds, particularly where modalities such as ice could be uncomfortable at times. There is also potential for arthritic pain and pain associated with bleeding to be confused. As management for arthritis and acute bleeding is very different, I wanted patients to be aware of this and to clarify with their treating clinicians if necessary. This poster is a simple display about a patient information brochure developed to help address these issues. The brochure gives guidelines on RICE specifically for those who already have arthritis as well as explanations as to why they are recommended.

POSTER 14

Name: Dr Rachel Bushing

Co-authors: Mrs Maureen Spilsbury

Institution/Organisation: Queensland Haemophilia Centre

Title of Abstract: Quality of Life in Severe and Moderate Haemophilia:
A Current Snapshot of the Qld Haemophilia Community

In early 2010 the Queensland Haemophilia Centre (QHC) applied to the Haemophilia Foundation Australia Research Fund for monies to conduct a Quality of Life (QOL) Assessment. The Centre was successful in the application and proceeded to receive approval from local Ethics Committees to conduct the Haem-A-Qol study at the Royal Brisbane and Women's Hospital. It was anticipated that the results would better inform the staff of the QHC about the current needs of the community.

The Haem-A-Qol was chosen as the primary measure of interest as it has good reliability (ranging from 0.74-0.88), and high convergent (with SF-36), and discriminant validities. Moreover, it is specifically designed to capture aspects of Quality of Life for adult patients with haemophilia. Attempts to secure a scoring template for the Haem-A-Qol proved to be challenging. Normative data for the Haem-A-Qol was sourced from the relevant literature providing an alternative plan as the official scoring template was unavailable.

A general demographics questionnaire was developed for participants in conjunction with the Haem-A-Qol to capture relevant data for the exploratory analyses. In conjunction with the Haem-A-Qol the demographic sheet sought to identify whether Quality of Life (QOL) was dependent upon a number of variables including age, the remoteness of the patients' residence and family structure. The study also explored whether higher ratings of QOL correlate with improved access to treatment and the establishment of prophylaxis within recent years of their treatment. Exploratory analyses were conducted on a range of other demographical variables including employment status / ethnic-background / gender etc., to determine any other significant associations with overall QOL.

Surveys were sent to people who were registered on the Queensland ABDR (Australian Bleeding Disorder Registry) and who were identified as having either Severe or Moderate Factor VIII or Factor IX Deficiency. The project was advertised in the Haemophilia Foundation Queensland Newsletter and non-responders were followed up to optimise response rates.

A comprehensive report of the project was drafted at each stage of the process. As completed questionnaires were received, all de-identified data was entered into a statistical package in preparation for analysis.

This poster will outline the process of administering the Haem-A-Qol at the Royal Brisbane and Women's Hospital and will present the findings at the completion of the project.

POSTER 15

Name: Dr Desdemona Chong

Co-authors: Joanna McCosker, Wendy Poulsen

Institution/Organisation: Royal Brisbane and Women's Hospital/ Royal Children's Hospital

Title of Abstract: Remote Control: Can Telehealth Replace Face-to-face Clinics for Rural and Remote Families?

The Children's Queensland Haemophilia Centre (QHC) is based at the Royal Children's Hospital (RCH) in Brisbane. The Centre provides a state-wide service which includes the provision of treatment, care and support by a multidisciplinary team. All children with inherited bleeding disorders who live in Queensland or Northern NSW are registered at the QHC. Because of the geographical diversity of families accessing the services of the Centre, regular outreach clinics have been developed to provide face-to-face contact for families in their local hospital settings at Nambour, Toowoomba, Gold Coast and Far North Queensland. In a new initiative, the QHC at the RCH also provides regular telehealth services to families living in the regions of Rockhampton, Townsville, Mackay, Cairns and Hervey Bay. Telehealth clinics function in a similar fashion to a face-to-face clinical consultation. When there is a need for a physical review, modern technology allows the camera to zoom as required, to closer view any region of the body, providing clear images for the medical team.

The telehealth service started in 2001 and 6 to 8 clinics are conducted every year. This service has been utilised by at least 20 families, with an increasing demand of this service observed. This partnership between the RCH and regional hospitals reaps benefits in many ways. Patients benefit from having access to regular clinic reviews at their local hospital at a lower financial cost and greater time efficiency compared to overall costs and implications of regular visits to the RCH in Brisbane. The telehealth sessions also provide an opportunity for medical teams across both the RCH and regional hospitals to discuss each case as required, thus augmenting communication between both teams.

To enhance clinical practice and patient satisfaction of users of the telehealth service, a survey was sent out to families to solicit their feedback and opinions. Results of the survey would be presented and further recommendations and implications for practice discussed.

Discussion with Poster Authors

Poster authors will be available at their poster the following times for discussion and questions:

Friday 21 October 13:00-13:15	Saturday 22 October 13:00-13:15
<p>POSTER 1 Claire Bell <i>Hepatitis C infection in adults attending the Haemophilia Centre of Western Australia: Current infection status and impact of hepatitis C</i></p>	<p>POSTER 7 Tara Skye Mooney <i>Mothers of Children with Haemophilia: An Exploration of Their Experiences</i></p>
<p>POSTER 2 Chantel Lauzon <i>The Extra Burden: Outcomes of the 2010 People with Haemophilia and Hepatitis C Survey</i></p>	<p>POSTER 9 Beryl Zeissink <i>Journal Club – keeping up with the evidence</i></p>
<p>POSTER 3 Suzanne O’Callaghan <i>The Wellbeing Weekend: learning to live well with hepatitis C for people with bleeding disorders</i></p>	<p>POSTER 10 P Fogarty (HFA), P Isarangkura (NHFT), J Spencer (HFA), M Suwannuraks (NHFT) <i>Collaboration through Twinning</i></p>
<p>POSTER 4 Dr Nyree Cole and Ms Judy Gilmour <i>The Experience of Portacath Use in Children Managed by the Auckland Haemophilia Centre over the last 10 years</i></p>	<p>POSTER 11 Dr Scott Dunkley <i>Effect of FEIBA on platelet aggregation and activation in severe haemophilia patients with inhibitors</i></p>
<p>POSTER 5 Janine Furmedge <i>I don’t want to hurt him – parents’ experiences of learning to administer clotting factor to their child</i></p>	<p>POSTER 12 Elizabeth J Hitchings <i>Oral health status of individuals with haemophilia. A review of the literature.</i></p>
<p>POSTER 6 Julia Ekert <i>Recording Home Usage of Clotting Factors-Asking patients and parents what they think</i></p>	<p>POSTER 13 Emma Paterson <i>RICE and arthritic joints in haemophilia</i></p>
<p>POSTER 8 Dr John Rowell, Dr Chris Barnes, Sharon Caris, Stephanie Gunn, Chris Hogan, Barbara Herden <i>Australian Bleeding Disorders Registry – A Collaborative Approach</i></p>	<p>POSTER 14 Dr Rachel Bushing <i>Quality of Life in Severe and Moderate Haemophilia: A Current Snapshot of the Qld Haemophilia Community</i></p>
<p>POSTER 15 Dr Desdemona Chong <i>Remote Control: Can Telehealth Replace Face-to-face Clinics for Rural and Remote Families?</i></p>	

CONFERENCE ABSTRACTS

FRIDAY 21 OCTOBER 2011

09:00-10:30

PLENARY 1 - How a happier body can lead to a happier mind -

Anna Louise Bouvier

Room: Freshwater Room 2&3

Anna Louise Bouvier

Physiocise

In whatever capacity haemophilia affects your life, either as a patient, a parent, a carer or a health professional, the physical, emotional and mental toll is significant. Often because of the need to focus on immediate issues there is a tendency to neglect personal wellbeing, which over time can lead to a depletion of one of your most important resources...you.

Physiotherapist and mind body expert Anna-Louise Bouvier has spent many years dealing with body breakdown as a result of physical and mental stress. She has taught thousands of people through her Physiocise program and her speaking programs how to recognize the physical signs of stress and “battle” fatigue and what simple strategies can be used to immediately improve health and wellbeing.

The scientific evidence for how your body can be used to improve mental health and wellbeing and decrease anxiety is now overwhelming. From physical exercise, to decreasing sedentary lifestyle, to improved sleep and finally to changes in posture and body awareness, you will leave this session with immediately applicable, tangible ways to a happier body and a happier mind.

FRIDAY 21 OCTOBER 2011

11:00-12:30

CONCURRENT 1 – Keeping the body in tune - children

Room: Freshwater Room 2

Chair: Wendy Poulson

Managing diet – dealing with fussy eaters

Dr Jacqui Dalby-Payne

The Children's Hospital at Westmead

Fussy eating is very common and considered normal toddler behaviour. Children in the second and third year of life often use food to exert control over their lives. Parents of fussy eaters will often engage in a daily battle over food with mealtimes lasting for up to 1 hour. Some will spend all day following their child around with food trying to sneak in mouthfuls. Children have the unique ability to match their intake to their caloric requirements and will refuse food when they are full. Their intake will vary from meal to meal and day to day. They are not usually selective of specific tastes and textures as you may see in a sensory food aversion. Growth is usually normal in the fussy eater and plotting the child's growth will reassure parents that their child's intake is adequate.

The following advice can be given to parents and carers of fussy eaters

- It is important to model normal eating behaviours at family meal times with the child sitting at the table with the rest of the family
- It may take 10 to 15 tries before a new food is accepted – offer the new food every other day
- Limit mealtimes to 30 minutes
- It is the parent / carers role to provide healthy, nutritious food and the child's role to decide how much and what to eat or whether to eat at all
- Never force feed a child and avoid coaxing or badgering the child during mealtimes
- Offer realistic, child-sized food portions
- Presenting meals as a tasting plate from which everyone in the family can choose what they want to eat will often encourage children to try a new food.
- Limit cow's milk to no more than 600ml per day as it can take away a child's appetite for solid food and is low in iron

Feeding disorders that can appear as a more extreme form of fussy eating but can result in failure to thrive include infantile anorexia, sensory food aversion and post-traumatic feeding disorder. It is important to recognise these conditions as their management differs. Speech pathologists, psychologists and dieticians with expertise in feeding can assist in managing children with these disorders.

Risk of bleeds associated with physical activity in children with haemophilia

Dr Carolyn Broderick

The Children's Hospital at Westmead & Faculty of Medicine UNSW

Background: The increased risk of bleeding associated with vigorous physical activity in children with haemophilia is not known. As a result, children with haemophilia and their families often receive conflicting advice as to whether or not they should play sport.

Methods: This study is a case-crossover study nested within a prospective cohort study. One hundred and four children with moderate or severe haemophilia A or B reported bleeding episodes once a week for a period of one year. Following a bleeding episode, the participant or parent/guardian was interviewed about exposures to physical activity in a case period 8 hours before the bleed, and 2 eight hour control periods. Conditional logistic regression was used to estimate the risk of participating in vigorous physical activity from measures of exposure to physical activity in the case and control periods.

Results: The mean incidence of bleeds was 5.4 per person-year. Category 2 activities (e.g. soccer, surfing) transiently increased rates of bleeding by a factor of 2.7 (95% CI 1.7-4.8, $p < 0.001$). Category 3 activities (e.g. judo, skateboarding) transiently increased rates of bleeding by a factor of 3.7 (95% CI 2.3-7.3, $p < 0.001$). Rates of bleeding were reduced by 2% for every 1% increase in factor level (95% CI 1% to 4%, $p = 0.003$). Most bleeds caused by physical activity manifest within one hour of activity.

Conclusions: Vigorous physical activity can trigger bleeding episodes in boys with moderate and severe haemophilia. Exogenous clotting factor will mitigate this risk. The quantification of bleeding risk will enable children with haemophilia and their families to make informed decisions about sports participation. It will also enable them to schedule prophylactic clotting factor administration around sports participation to reduce the risk.

Personal Experience

Chris Gordon

VIC

I am a 21 year old haemophiliac from Melbourne. Diagnosed at birth. I have a Passion for sport and AFL. Like every young boys dream, I wished to one day enter the MCG with a roaring 100,000 fans. In my eyes the dream never felt out of reach. The only problem was, the sport I loved and the arena I dreamt to walk out onto was taken away by this blood disorder which was haemophilia. As a child I was oblivious to the risks and although doctors and my parents denied football involvement, I never fully understood the situation and continued to play with friends at lunchtimes still believing that the dream is alive....

FRIDAY 21 OCTOBER 2011

11:00-12:30

CONCURRENT 2 – Staying on your feet – a session for adults of all ages

Room: Freshwater Room 3

Chair: Dr Huyen Tran

Saving the Ankle Joint

Dr Sanjeev Gupta

Royal Prince Alfred Hospital, Sydney

Ankle arthritis is a potentially disabling condition. It generally affects a younger patient population, and often can have bilateral involvement. Fusion of the ankle joint has remained the gold standard for treatment, should non-operative treatments fail. Increasingly, ankle replacement has gained popularity. It allows maintenance of ankle range of motion, and improved gait profile. Although not yet enjoying the same success as hip and knee replacements, ankle replacement surgery is potential alternative in the appropriately selected patient.

Haemophiliac joints in children: can we preserve them from damage?

A/Prof Prudence Manners

University of Western Australia and Princess Margaret Hospital for Children

Joints of haemophiliac children are particularly prone to the destructive effects of Intra-articular bleeds. Destroyed joints seriously effect the quality of life evermore for that individual. Hence prevention of damage is a priority in the haemophiliac child.

The use of prophylactic factor VIII significantly reduces joint bleeding but does not prevent it completely.

When joint bleeds occur, at Princess Margaret Hospital for Children our policy is to remove the blood as quickly and as completely as possible thereby preventing the chain of events that sets up a cycle of damage in the joint. Under cover of factor VIII, the blood is aspirated from the joint which is then washed out with normal saline. Intra-articular corticosteroid injection follows.

There is evidence in our patient cohort of much improved joint preservation despite joint bleeding with this strategy of early intervention.

There have been no episodes of infection following the procedure.

There is an expectation that none of the patient cohort will require joint replacement, and we hope very few will later require synovectomy for chronic inflammation.

The evidence is there that a paediatric rheumatologist should be included as a valuable member of the multi-disciplinary team caring for children with haemophilia.

Haemophilic joints in adults: can we preserve them from damage?

Dr Ann Powell

The Alfred, Melbourne

Haemophilic arthropathy continues to be a major problem encountered by adults with moderate to severe haemophilia despite the improved access to product. Problematic joints tend to be those worst affected during childhood and the focus of treatment as an adult is to slow ongoing damage and improve function.

A Multidisciplinary clinic was formed at the Ronald Sawers Haemophilia Unit at the Alfred Hospital which includes a haematologist, rheumatologist, physiotherapist, nurse practitioners, social worker and pain physician. Strategies such as optimising product usage, cortisone injections, yttrium synovectomy, appropriate strength training and analgesia are employed routinely. Patients resistant to routine care are assessed for surgical interventions such as joint replacement and ankle fusion.

Due to the lack of published data on conservative strategies, we are currently looking at their efficacy and safety in our adult population. Information currently being collected includes pain scores, functional status and range of movement before and after any interventional procedures. Further information looking at the use of power duplex, MRI and PET CT post yttrium synovectomy are being looked at as modalities to best direct joint treatment.

How to keep going – exercise/falls/balance – a practical approach

Emma Paterson

Queensland Haemophilia Centre, Royal Brisbane and Women's Hospital

This session is a practical approach to healthy exercise for people with bleeding disorders, whilst providing strategies for reducing falls and improving balance.

Focus is on healthy exercise for the spectrum of levels of ability. Discussion includes: What is healthy exercise? How much is enough? Falls prevention for those at high risk, and the importance of early prevention of arthropathy and associated weakness. There will also be discussion of exercise programmes run out of the Royal Brisbane and Women's Hospital, including a new program targeting younger adults with Haemophilia.

Many people with haemophilia can become disenchanted with exercise due to potential for exacerbations of bleeding when exercise is too intense, or simply frustrated by limitation in activity. This presentation will provide practical solutions to enable and encourage participation, and to optimise physical health and wellbeing through appropriate exercise.

FRIDAY 21 OCTOBER 2011

11:00-12:30

CONCURRENT 3 – Von Willebrand Disorder

Room: Parklands

Chair: Dr Susan Russell

A personal story of a family affected by VWD

Manal Awad

NSW

(Abstract not available at time of printing)

VWD – clinical update on treatment and care

Dr Mandy Davis

The Alfred, VIC

(Abstract not available at time of printing)

Diagnosis and classification of VWD

Dr Emmanuel J Favaloro

Institute of Clinical Pathology & Medical Research, Westmead Hospital

Von Willebrand disorder (VWD) is the most common inherited bleeding disorder and arises from deficiencies and/or defects in the plasma protein von Willebrand factor (VWF). VWD is classified into 6 different types, with type 1 identified as a (partial) quantitative deficiency of VWF, type 3 defined by a (virtual) total deficiency of VWF, and type 2 identifying four separate types (2A, 2B, 2M, 2N) characterised by qualitative defects. The classification is based on phenotypic assays including FVIII, VWF:Ag and VWF activity, typically by ristocetin cofactor (VWF:RCo), but also increasingly by collagen binding (VWF:CB). Phenotypic testing may be supplemented by multimer analysis, ristocetin induced platelet agglutination (RIPA), and VWF:FVIII binding. Although genetic analysis is not required to diagnose VWD or to define a classification type, it may be useful in discrete situations. This talk will review this diagnostic process, with a focus on newer approaches, including extended test panels and the use of data from desmopressin challenges as a diagnostic tool.

FRIDAY 21 OCTOBER 2011

13:30-15:00

CONCURRENT 1 – Keeping the mind and body in tune - adults

Room: Freshwater 2

Chair: Andrew Atkins

Obesity/weight management: clinical issues

TBC

Personal experiences: Andrew Selvaggi and Zev Fishman will share their inspiring stories of overcoming some of the complications of haemophilia

Andrew Selvaggi

VIC

A view into the life of a young adult growing up with severe haemophilia A with Inhibitors. An inside look into school, high school, work, social, love and general life with haemophilia. But most of all, how haemophilia isn't something that holds you back from loving and living life.

Currently working in the health industry Andrew knows first hand the benefits of health and fitness when living with haemophilia.

Zev Fishman

VIC

I will give a brief history of my life as a 60 year old person with severe haemophilia. One point that I will make is the comparison between my first 16 years of “no treatment” that I experienced in the 50's and 60's and the current plight of 70% of all people with haemophilia in the world that either aren't diagnosed or not treated. I will emphasize what an amazing experience it was to go to Buenos Aires and to be part of the world of haemophilia, and so grateful that I live in Australia. Regardless of the difficulties that we may face as a person with a bleeding disorder we have the options in this country to live a very normal life, to have a job and a family. I will also reflect on the lead up to my amputation and how successful the outcome was and that it has given me a new lease on life. The option can be seen as a positive not a negative.

Creating flourishing lives: putting positive psychology into practice

Nicola Gates

Positive Psychology Institute

The World Health Organisation states that health includes mental and social well-being. Positive mental health and well-being are things we can all benefit from as they take us from surviving in life to thriving. This presentation will introduce a model from positive psychology that describes the keys to positive mental health, meaning and flourishing lives. The latest evidence from neuroscience and psychological research that support the model will be demonstrated along with practical strategies and suggestions of how to improve your own sense of well-being.

FRIDAY 21 OCTOBER 2011

13:30-15:00

CONCURRENT 2 – Women’s health and reproduction

Room: Freshwater 3

Chair: Belinda Burnett

IVF and embryo diagnosis

Dr Kristi Jones

The Children’s Hospital at Westmead

IVF and Pre-implantation Genetic Diagnosis: Over the past 20 years, there have been remarkable advances in pre-implantation genetic diagnosis (PGD). This technology allows couples where a serious genetic disorder affects them or a family member, to combine IVF with genetic testing of embryos prior to transfer to the uterus. PGD is now offered as a choice for couples planning a family. It allows an alternative to prenatal genetic testing on a growing baby. I will discuss the scientific and medical aspects of the PGD process, and give examples of situations where couples have used this option.

Managing menorrhagia

Dr Claire McLintock

Auckland City Hospital

Heavy menstrual bleeding (menorrhagia) is the commonest bleeding symptom reported in females with inherited bleeding disorders. Targeted surveillance of female hemophilia treatment centres in the US reported that heavy menstrual bleeding was experienced in 76% of menstruating females. Conversely, a high proportion of women with menorrhagia have undiagnosed bleeding disorders, as gynecologists are often unaware of which other bleeding symptoms can be helpful in identifying affected women. Also women tend to judge what is “normal” menstrual blood loss to what their mothers or sisters have – so in a family where many women have inherited the bleeding disorder, “normal” can be decidedly “abnormal”.

Methods used to treat menorrhagia such as the oral contraceptive pill, DDAVP, tranexamic acid, the levonorgestel-releasing intrauterine system (Mirena IUD) and show variable efficacy but show promise in hopefully reducing the need for hysterectomy later in life for women with severe menorrhagia. Management of menorrhagia is particularly difficult when women wish to conceive.

HFNZ Women’s Program

Lynne Campbell

Haemophilia Foundation of New Zealand

In recent years there has been increased recognition of the unique issues faced by women with inherited bleeding disorders. In New Zealand, HFNZ have employed a range of approaches to increase awareness and understanding of these issues.

After trialing targeted education workshops for young women and mothers and daughters, HFNZ surveyed their female membership to better understand their needs. This survey informed the development the 2009 Women's Workshop, which will be the main focus of this presentation.

The aims of the 2009 Women's Workshop were increased information and education, empowerment, and networking or the development of a sense of community among women with a bleeding disorder or who carry the gene for haemophilia.

The 2009 Women's Workshop has been the most successful initiative for women in New Zealand. Forty-one women aged between 16 and 80 years attended the residential weekend workshop, including 8 women with von Willebrand disorder and 33 women with haemophilia or who carry the haemophilia gene. While education was the main focus of the programme, recreational activities and time for bonding was incorporated.

Overall, participants valued the opportunity to get together and came away with a greater understanding of issues and options related to their bleeding disorder. Including a wider range of ages and a wider variety of education topics proved to be a successful formula. HFNZ recognise the value of education for this important segment of our bleeding disorders community and are committed to providing further targeted initiatives to meet their needs.

FRIDAY 21 OCTOBER 2011

13:30-15:00

CONCURRENT 3 – Transitions: becoming an adult

Room: Parklands

Chair: Maureen Spilsbury

“Transitioning in Queensland: From Teddy Bears to Apprenticeships!”

Maureen Spilsbury & Dr Desdemona Chong

Queensland Haemophilia Centre

The Queensland Haemophilia Center is currently in the enviable situation of having both the Paediatric and Adult hospitals on the same site. The Royal Brisbane & Women’s Hospital and the Royal Children’s Hospital are joined by a common walkway. This allows for optimum levels of communication between staff. The physical setting also provides the opportunity to work on joint projects to streamline issues such as transition from paediatric care to the management of inherited bleeding disorders of young adults. Transition has been defined as “a multi-faceted, active process that attends to the medical, psychosocial, and educational/ vocational needs of adolescents as they move from child to adult centred care”. It is a multidimensional process with transfer to adult care as only one event within that process. This session will look at the way in which the transition process has been

WA Transition program

Sharon Hawkins, Haemophilia Centre of WA and William Oversby

Outline

The paediatric and adult Haemophilia Treatment Centres (HTC) in Perth are located in separate hospitals. A formal transition pathway for young people to gradually receive education to increase independence in health care in preparation for a planned move from paediatric to adult services, had not been implemented. In response to concerns that young people were attending their first adult clinic with limited knowledge of their bleeding disorder and with little preparation for the differences between HTCs, a Quality Improvement Project was undertaken to examine how transition may be improved. Patients who had already moved to the adult facility in the last ten years completed two surveys and were interviewed by the Haemophilia Counsellor following guideline questions on psychosocial and environmental issues around transitioning. One survey examined patient satisfaction with adult HTC services and a musculo-skeletal survey noted the patient’s joint status and self-management of bleeds.

Conclusion

The findings of the psychosocial component of the project, which examined patient’s readiness to transition, will be discussed. Recommendations were made for improved service provision and have been implemented to address the transition issues identified through the surveys and interview. A more formalised process of transitioning patients has been developed and the practice implications will be discussed. A personal story will be presented by a patient of his experience of transitioning from paediatric to adult HTC post implementation of the more formal transitioning program.

FRIDAY 21 OCTOBER 2011

15:30-17:00

PLENARY 2 - Ageing

Room: Freshwater Room 2&3

Chair: Zev Fishman

Haemophilia and Ageing

Dr Mike Makris

Sheffield Haemophilia and Thrombosis Centre, United Kingdom

One hundred years ago the average life expectancy of a person with haemophilia (PWH) was 12 years of age with most affected individuals dying from spontaneous or traumatic bleeding including after dental extraction and circumcision. Today the life expectancy of an HIV negative PWH is approaching that of the normal population. As affected individuals get older they encounter the problems of old age in the normal population including cardiovascular disease, malignancy, falls and osteoarthritis. This is of course on top of haemophilia related morbidity which is primarily related to haemophilic arthropathy as a result of multiple joint bleeds and the long term effects of HIV and Hepatitis C infections. HIV can be controlled and Hepatitis C cleared in 40-60% of PWH. Knee, hip and elbow and shoulder joints have been amenable to replacement for some time but now ankle replacements are also increasingly being performed. Hypertension appears commoner in PWH but the reduced mortality from cardiovascular disease is probably not due to less atherosclerosis. A particular challenge for haemophilia treaters is the management of heart attacks and strokes when occurring in PWH where anticoagulant treatment may be required. Although malignancy is not commoner than expected in PWH (with the exception of hepatocellular carcinoma in chronic hepatitis C and lymphoma in HIV positive individuals), its management once diagnosed is sometimes problematic if high dose chemotherapy is required. Increasingly in the future, the management of a PWH will entail a multidisciplinary team approach that will often be different from that experienced today.

Followed by multidisciplinary panel:

Steven (Nurse), Leonie (Social Worker) and Ian (Physiotherapist) will discuss the implications for Ageing for people with bleeding disorders and their families and carers. They will draw on their work in the field over many years.

Leonie Mudge (Social Worker)

Leonie Mudge has worked as a Social Worker with the bleeding disorders community for many years. She has experience in both Victoria and NSW, and has been employed by a Haemophilia Foundation, working within the community and employed by a Health Dept in an acute hospital setting.

Ian d'Young (Physiotherapist)

Ian is currently employed by the ADHB as the advanced physiotherapy practitioner for haemophilia and is the NZ national clinical lead for haemophilia physiotherapy. He is co-chair of the Australia/New Zealand Haemophilia Physiotherapy Group and was elected to the national executive of Physiotherapy New Zealand in 2011. He is an experienced haemophilia clinician having previously worked as the haemophilia clinical specialist at the Centre for Haemostasis and Thrombosis at St Thomas' Hospital in central London.

Stephen Mathews (Nurse)

Haemophilia clinical nurse consultant working in the HTC at Royal Prince Alfred Hospital.
haemophilia B.

SATURDAY 22 OCTOBER 2011

09:00-10:30

PLENARY 3 – Treatment Challenges

Room: Freshwater Room 2&3

Chair: Dr Scott Dunkley

Safety of current products used to treat inherited bleeding disorders

Dr Mike Makris

Sheffield Haemophilia and Thrombosis Centre, United Kingdom

Safety and efficacy are the two most important qualities to be considered in choosing a clotting factor concentrate to treat inherited bleeding disorders. Following the HIV and Hepatitis C tragedies of the 1980s, safety remains an important issue for the haemophilia community. The current products are the safest they have ever been but we must not be complacent. Manufacturers continuously strive to produce purer and safer products. In theory each country has systems to report adverse events that occur following treatment with a particular product but in practise these are not often used and have not been particularly useful in the field of inherited bleeding disorders. In this presentation the European Haemophilia Safety Surveillance System (EUHASS) will be described and the first two years of data will be shown. EUHASS is a prospective adverse event reporting system in the field of inherited bleeding disorders. 64 haemophilia centres from 27 European countries participated in the first two years of the project. The events reported are allergic or acute reactions, transfusion transmitted infections, inhibitors, thromboses, malignancies and deaths. The system is electronic and is easy to use. At present only haemophilia treaters are able to report the events. Each year the haemophilia centres report on the total number of persons with each diagnosis registered at their centre and the number treated with each specific concentrate. Further information on EUHASS is available at the website www.euhass.org

Current and emerging challenges, risk factors for inhibitor development

Dr Julie Curtin

The Children's Hospital at Westmead

With the advent of improved factor concentrates and viral inactivation, the risk of viral infection from factor concentrates is greatly diminished. The development of an inhibitor is today the most serious complication of the treatment of haemophilia. Inhibitors are reported to occur in 20 – 30% of patients with haemophilia A and 5% of patients with haemophilia B. In order to minimise inhibitor development it is necessary to understand risk factors for inhibitor development. Some risk factors are strongly associated with inhibitor development, others are weaker risk factors. Our understanding of these risk factors continues to evolve. Risk factors can be classified into patient related and environment related. The patient related risk factors include genetic mutation, ethnicity, family history of inhibitor development, and immune response genes. Unfortunately whilst some of these are quite strong risk factors there is little we can do about these risk factors. The impact of environmental

risk factors are less clear. Suggested environmental risk factors include peak treatment moments, immune system challenges such as surgery, concentrates used and mode of delivery. An understanding of these environmental risk factors is important because it potentially offers an opportunity to modify the patient's risk of inhibitor development. The evidence around these risk factors will be presented. Furthermore potential strategies currently being proposed to minimise the risk of inhibitor development will be presented.

Update from the AHCDO Tolerisation Advisory Committee

Dr Chris Barnes

Royal Childrens Hospital, Melbourne

The Tolerisation Advisory Committee (TAC) provides a resource and advice on cases of immune tolerisation for patients with haemophilia and inhibitors in Australia via monthly telephone conferences. All cases of ITT in Australia are encouraged to be reviewed at the TAC. Members of the TAC collect information on cases and provide peer review. The current presentation will provide an update on cases referred to the TAC.

Inhibitors in mild haemophilia

Dr Simon McRae

Royal Adelaide Hospital

Inhibitor formation is an increasingly recognized problem in patients with mild haemophilia, occurring in approximately 5 % of individuals with this condition. Inhibitor development can be associated with a change in bleeding pattern to one more consistent with severe haemophilia A, due to activity of the inhibitor against the patients own factor VIII. Emerging evidence is accumulating regarding risk factors for inhibitor development in mild HA, with particular factor VIII gene mutations and intensive FVIII exposure appearing to increase risk. Knowledge of these risk factors may be used to guide management in particular individuals. This presentation will overview the above issues, as well as briefly discuss management of patients with mild HA in whom inhibitors develop.

A personal experience of tolerisation

Hamish Robinson

NSW

Diagnosed at 11 months due to a "golf ball" bruise on my forehead that just wouldn't go away, and impossible to stop growing as I thought I was a rhino, with a factor level of 2%. Tolerisation started after I was given a trilumin catheter for my 9th birthday and was on a modified Malmö procedure. Since my successful tolerisation I have had no major problems unless I don't have my 2nd daily prophylaxis.

SATURDAY 22 OCTOBER 2011

11:00-12:30

CONCURRENT 1– Men’s Business

Room: Freshwater Room 2

Chair: Sharon Hawkins

Facilitator: Greg Millan

What’s normal? – across the lifespan

Greg Millan

Men’s Health Services

Enjoying your sex life: Issues and solutions for men with physical impairment

Dr Tinashe Dune

University of Sydney, Faculty of Health Sciences

Satisfying sexual experiences are integral to Quality of Life (Stewart, 2009). According to the World Health Organization (2011), “sexuality is a central aspect of being human...and encompasses sex, gender identities and roles, ... eroticism, pleasure, intimacy and reproduction”. However, some men with physical impairment may have more to consider when negotiating and navigating satisfying sex than their typical peers (Dune, 2011). This presentation focuses on possible solutions to some of the issues men with physical impairment experience when trying to fulfil their sexual wants and needs. Some issues for men with physical impairment include: physical limitations and reduced sexual function, restricted access to sexual and reproductive health information, expectations of masculinity, and the attitudes of others (Dune, 2011). Possible solutions include: managing sexual expectations and goals, engaging health care professionals in discussions about your sexuality, communicating your sexual wants, needs and frustrations with sexual partners and exploring your sexuality (Gianotten & Heijnen, 2009).

Panel – Q&A

Haemophilia physiotherapist – Cameron Cramey

Senior Musculoskeletal Physiotherapist at the Royal Adelaide Hospital. Special interest in spinal dysfunction and injury prevention and management in the adult bleeding disorder population. Also work part time in musculoskeletal sports private practice.

Haemophilia nurse – Clare Waite

Clare Waite is a haemophilia nurse at Royal Prince Alfred Hospital in Sydney. She has specialised in haematology for ten years and specifically in haemophilia for the last four of those years.

Haemophilia Counsellor - Sharon Hawkins

Sharon is a Social Worker and works as the Haemophilia Counsellor at the Haemophilia Treatment Centre of Western Australia. Sharon has been working in this position since 2004 and works with adults and children with inherited bleeding disorders within the hospitals and the community.

BBV's, and body image - Dr Roger Garsia

Dr Garsia is Staff Specialist Clinical Immunology, RPAH; Set up the first clinic in NSW for people with haemophilia who had been exposed to the risk of HIV by contaminated coagulation factors. Director of HIV/AIDS Services for Sydney Local Health District. Chairman NSW Ministerial Advisory Committee on HIV/ AIDS/ STI; Research interest in viral evolution and immune response to the changing virus.

SATURDAY 22 OCTOBER 2011

11:00-12:30

CONCURRENT 2 – The challenges of Prophylaxis

Room: Freshwater Room 3

Chair: Ian d'Young

Clinical update on prophylaxis

Dr Alessandro Gringeri

(Abstract not available at time of printing)

Delivery of Prophylactic Factor to Children with Severe Haemophilia: the challenge of venous access

Dr Susan Russell & Robyn Shoemark

The Children's Hospital at Westmead

Prophylaxis, usually delivering 2 or 3 doses of factor intravenously per week, for patients with severe and moderate haemophilia is seen as the gold standard of care for preventing bleeding. Commencing prophylaxis isn't always met with anticipation and there are many questions that will arise in discussion. Do we have to do it? When do we start? How do we do it? What if I can't do it? What if my child won't sit still? I don't like needles so can't we just wait a bit longer? How will I learn? How will my partner learn? How will my child learn? What is venepuncture? What is a central venous access device or a port?

Venepuncture is the preferred method to deliver prophylaxis. When able to be performed, it is the quickest and safest method of administering treatment. But sometimes, this is fraught with problems such as poor venous access, the age of the child, mindsets of both parent/carer and the child and the frequency of treatment.

What are the other options? A central venous line or a port? These also have their own set of challenges: insertion requires an operation under general anaesthetic, the family need to learn a sterile procedure to prevent infections, and there are the risks of bleeding at the access site, thrombosis and blockage. What happens if we get an infection? What do we do if the port blocks?

How do we best manage the delivery of prophylaxis? Education is the key and involves discussions with the treating haematologist and nurse.

This presentation will endeavor to answer questions regarding the challenges surrounding delivering prophylaxis, in particular the method of delivery using either venepuncture or a central venous access device.

Joint health for children and adolescents: Prophylaxis is not the only answer

Ian d'Young

Auckland District Health Board

This presentation covers the nature of joint bleeding and the relationship between altered limb biomechanics, a higher risk of bleeding and accelerated joint damage. Joint bleeds are not spontaneous – there is always a reason why the synovium that lines the joint is damaged – so it is important for young men and families to understand the nature of joint bleeding and what can be done to both minimise these and manage them effectively once they occur.

Prophylaxis is an important part of this process however it is only one link in the chain and must be complimented by appropriate physical activity and exercise. The rationale for rapid reporting and management of all bleeding episodes, the importance of rehabilitation and the need to maintain physical fitness and a healthy lifestyle in order to minimise the risk of bleeding in young men are all presented here.

SATURDAY 22 OCTOBER 2011

11:00-12:30

CONCURRENT 3 – The rarer bleeding disorders

Room: Parklands

Chair: Grainne Dunn

A personal story by a mother of a child with severe factor XI deficiency

Nadine Penn

NSW

(Abstract not available at time of printing)

Nursing perspectives – 3 nurses will present snapshots of their experiences of looking after patients with rare bleeding disorders and the nursing issues that arise:

Acquired haemophilia

Andrew Atkins

Royal Adelaide Hospital, SA

Acquired haemophilia A is an autoimmune process where an inhibitor (antibody) to factor VIII develops and reduces factor FVIII plasma levels. Like hereditary haemophilia it is often manifested by spontaneous bleeding. This case presentation considers some of the challenges faced in managing acquired haemophilia due to treatment complications and pre-existing medical conditions.

Afibrinogenaemia

Olivia Hollingdrake

Royal Brisbane and Women's Hospital

A case-study of two brothers living with Afibrinogenaemia, a rare bleeding disorder. The presentation will focus on the effects and treatment of Afibrinogenaemia throughout the lives of the brothers to date.

Glanzmann's

Penny McCarthy

The Alfred hospital

A case study of a young woman living with Glanzmann thrombasthenia, a rare bleeding disorder. This presentation will concentrate on the complex decisions involved in her desire to start a family

Factor X deficiency

Dr James Price

Princess Margaret Hospital for Children

Factor X deficiency is a rare autosomal recessive bleeding disorder with an incidence of 1:1,000,000 of the general population. The severity of the disorder varies considerably, but the severe cases present early with significant bleeding including umbilical stump and intracerebral haemorrhages. Bleeding in newborns can be life-threatening and urgent diagnosis and therapy is needed. Treatment with fresh frozen plasma or prothrombin complex is effective but the latter may be associated with a thrombotic tendency. A plasma concentrate of factor X is available for severe factor X patients. Factor X has a long half life (20 – 40 hours) and prophylaxis with once or twice weekly infusions of factor concentrate is effective. Factor X is a vitamin K dependant factor and is synthesized in the liver. The factor X gene is on chromosome 13 downstream from the factor VII gene. Missence mutations of the factor X gene are the most common cause, but nonsense mutations and large deletions may be seen. Heterozygotes (1:500 of the population) are usually asymptomatic but some have a mild bleeding disorder. Epistaxis, menorrhagia, post-operative bleeding and haemarthroses are the most common symptoms in patients with a moderate deficiency of factor X. Acquired factor X deficiency occurs in liver disease, vitamin K deficiency and in association with amyloidosis.

Platelet function disorders

Dr Tim Brighton

SEALS, Prince of Wales Hospital Sydney

A diagnosis of “Platelet Function Disorder” encompasses a clinical diagnosis of abnormal muco-cutaneous bleeding which may or may not be supported by abnormal laboratory evaluation of platelet function. In this talk I will present a concise summary of platelet function and overview the known “platelet function disorders” with a description of their clinical presentation, laboratory evaluation and management. Recent work in the assessment of storage pool disorders by electron microscopy will be presented.

SATURDAY 22 OCTOBER 2011

13:30-15:00

CONCURRENT 1 – Living with hepatitis C and/or HIV co-infection

Room: Freshwater 2

Chair: Megan Walsh

From a patient's perspective

Luke Ahern

NSW

Medical update on HIV co-infection including reproduction for HIV discordant couples

Dr Roger Garsia

Royal Prince Alfred Hospital

Uncertainty about the long-term prognosis of HIV, coupled with the complicating factor of chronic viral hepatitis, led many men with haemophilia and HIV to defer pregnancy. Successful virus controlling treatment of HIV and in many cases eradication of hepatitis C have changed the landscape such that families have been considering and following a range of approaches in dealing with conception, genetic diagnosis and management of HIV and hepatitis risk. International studies of risk of heterosexual transmission of HIV and the effect of treatment with HAART provide grounds for optimism that a risk management approach to conception may be almost as safe as an IVF approach for mother and baby where the male is HIV infected. In general curative treatment of hepatitis C should precede conception by a prolonged period to minimize the risk of a blip of viral (HIV) replication and to allow reconstitution of immunological competence after the lymphocyte depleting effects of interferon have subsided.

Update on hepatitis C and treatment

A/Prof Simone Strasser

Royal Prince Alfred Hospital

The current standard treatment for people with chronic hepatitis C infection involves weekly injections of peginterferon and twice daily capsules with ribavirin. Treatment is associated with viral clearance in approximately 40-70%, depending on viral genotype. New treatments are coming to clinical practice for people with Genotype 1 infection in particular, and significantly improve response rates when given with PegIFN and ribavirin. The likelihood of response to treatment can be predicted by pretreatment assessment of liver fibrosis (scarring) with a non-invasive assessment (Transient Elastography or Fibroscan) and with testing of the patients IL28B status (a marker of interferon responsiveness). Untreated, hepatitis C can lead to cirrhosis of the liver, liver failure and liver cancer in some people. It is recommended that all people with hepatitis C be assessed for antiviral treatment.

Managing symptoms and liver health

A/Prof Frances Tenison

(Abstract not available at time of printing)

Saturday 22nd October 2011

SATURDAY 22 OCTOBER 2011

13:30-15:00

CONCURRENT 2 – Caring for parents and carers

Room: Freshwater 3

Chair: Dr Desdemona Chong

Taming the Stress Dragon

Dr Desdemona Chong

Queensland Haemophilia Centre

Parents wear multiple hats and perform many roles in their lives. Having a child with a chronic condition means that parents need to make further adjustments to cope with the demands of caring for the child. If not managed well, this can create a lot of stress and tension for parents. This session is not about parenting per se, but about self-care for parents. The session provides a broad overview of what stress is and the different stress coping styles used by individuals. It also looks at practical ways of stress management and chronic disease management. The aim is for parents to gain a better insight into their coping styles and therefore, equip themselves with strategies that can help them care for their children more effectively and achieve a better work-life balance.

Empowering Parents!

PEP in Australia

Anne Jackson

Women's & Children's Hospital, Adelaide

Aim:

To highlight the benefits of providing parent centred programs to improve parents' ability to cope with the challenges of raising a child with haemophilia.

Discussion:

The challenges of raising a child with haemophilia impact on the whole family. How parents cope with these challenges often influences the relationships that develop within families, within the community and the child's perception of self. Health professionals often focus on providing education on the medical and physical management of having a child with haemophilia, i.e. how to recognise and treat bleeds, rather than the social and family aspects of care. In contrast the Parents Empowering Parents (PEP) program offers tools for parents to use that enable them to build a relationship with their child that is supportive and encouraging. This is done by establishing goals for both their child and how they parent. PEP empowers parents by helping them identify their thoughts and feelings about their child's diagnosis of haemophilia and their own experiences of parenting. PEP offers skills to effectively parent leading to confident, successful, happy children.

A PEP program was offered to families in SA and 11 parents attended the 3 day program. Two parents combined to present important elements of the program. They also shared their first hand experiences of parenting which was integral in the learning of parents that attended. The parents' motivation for attending, as well as the benefits they experienced, will be discussed from both the participants and facilitator's perspective.

Conclusion:

Implementing parenting programs specifically designed to address the challenges of parenting a child with haemophilia provides support and is beneficial; to the individuals attending and to the relationships they are developing with their child and how families manage.

Re-PEP in New Zealand – an opportunity to review, re-visit, reflect and refresh
Colleen McKay

Haemophilia Foundation of New Zealand

The Parents-Empowering-Parents (PEP) Programme was designed to educate parents of children with bleeding disorders and improve confidence in parenting skills. Originally developed in the USA, the programme is presented by parents of children with bleeding disorders, in tandem with a social worker and nurse. The Haemophilia Foundation of New Zealand (HFNZ) has held two PEP programmes in 2008 and 2009, and in 2010 PEP graduates were invited back to the first ever Re-PEP programme.

The two-day Re-PEP programme aimed: to revisit PEP principles and provide a forum for self-evaluation; to further develop parenting skills in order to revitalise parenting; and to provide a forum for a PEP parent graduate reunion for renewing mutual support networks.

Fifteen of the 20 NZ PEP graduate parents attended Re-PEP (75%). The programme, developed by HFNZ, was facilitated by two Outreach Workers and a Haemophilia Nurse. Together, parents reviewed the concepts of PEP and discussed the value of the programme, revisited their world view, parenting styles and had the opportunity to reflect on and rewrite their family blueprint. Participants felt the PEP and Re-PEP programmes guided them to empower their children to be honest, independent and self-reliant people who are able to make sensible and well thought-out choices for their own safety, wellbeing and role in the family's wider community. They recommended PEP to all parents with or without bleeding disorders. Several Re-PEP participants have gone on to train to become PEP facilitators. HFNZ plans to run their next PEP programme in 2012.

The benefits from a Mother's perspective - Lynley Scott

The benefits from a Father's perspective - Richard Scott

Haemophilia Foundation of New Zealand

The Parents-Empowering-Parents (PEP) Programme was designed to educate parents of children with bleeding disorders and improve confidence in parenting skills. In 2010, HFNZ organised a RePEP programme to bring New Zealand PEP graduate parents back to re-visit and reflect on PEP principles and concepts. This presentation will give both a mother's and a father's perspective of two participants of the RePEP programme.

The PEP programme challenges parents to think about their parenting and their role in shaping the character and values of their children. As a result of participating in PEP, they have become more consistent in their parenting and focused on the characteristics they want their children to have as adults. The consequence of this has been more effective and meaningful discipline and an increase in their children's self-esteem.

The communication skills learned as part of the programme has benefitted their marriage and led to a better understanding of each other's world view and how these were shaped by their experiences.

Revisiting PEP principles and activities provided encouragement and renewed motivation to review how well they had done in achieving their family goals. RePEP was also an opportunity review how their parenting had changed from when they first participated, set more goals together and further improve the techniques so that they could plan the best future possible for their children. The presenters highly recommend PEP to all parents with or without a child with haemophilia or a bleeding disorder. They have become so passionate about the PEP programme that they have become parent trainers themselves.

Caring for Carers across the spectrum

Elena Katrakis

Carers NSW

Carers NSW, as the peak body for carers, aims to improve opportunities for carers and ensure they have access to services that meet their needs regardless of their age, gender, circumstances, location or cultural and linguistic backgrounds.

The National Survey of Carers Health and Wellbeing (2007) found that carers have the lowest levels of wellbeing of any Australian group and more than one third of carers experience severe or extreme stress. Caring is often long term with a third of carers caring for more than ten years. Caring can be demanding physically, emotionally, financially and socially and often carers are so concerned about the person they care for they fail to look after themselves. Carers can come to define themselves as a carer and neglect other aspects of their lives, including their own health. This session will outline strategies carers can use to manage stress and preserve their social, physical and emotional wellbeing. There will also be discussion of services, like counselling and respite, which carers can access to help them in their caring role.

SATURDAY 22 OCTOBER 2011

13:30-15:00

CONCURRENT 3 – Communication and Social Media

Room: Parklands

Chair: Jonathan Spencer

Social networking – community perspectives and issues to consider for community organizations

Suzanne O’Callaghan

Haemophilia Foundation Australia

Social media technology such as Facebook and Twitter is a relatively new communication medium. It can offer both adults and young people in the bleeding disorders community many benefits: the opportunity to connect with Haemophilia Foundations or other community members in similar situations, seek advice, share stories, stay in touch with the latest information, and join online activities. Importantly, community members can connect when needed or convenient.

However, social media technology platforms have also raised a number of concerns: how to protect privacy, the potential for inaccurate or inappropriate advice, and vulnerability to stalking and cyber bullying.

For community organisations, managing the benefits and risks of using social media technology to communicate with community members is a careful balance. Social media platforms enable organisations to connect with community members who are already active in these platforms, to hear and respond to their questions in a timely and informal way and engage community members of all ages with current programs. Before establishing a social networking presence, eg on Facebook, an important step for an organisation is to consider its capacity to manage risks in a productive way: risks to the safety of community members and to the organisation’s reputation. This involves working through questions such as who will moderate the community comments and how; how to protect community members’ privacy, how to respond to questions, what boundaries to set and establishing some organisational policies and procedures.

Sharing knowledge and experience with using these platforms will be valuable for community organisations to find positive ways to manage an online presence. As social media technology continues to evolve, it will be an ongoing challenge but also an exciting opportunity for community organisations to develop techniques so that these platforms can be used effectively.

Ethics & impact of social networking for health professionals/doctors
TBC

Privacy and reputation management in the digital space

Melissa Sevil

Australian Federal Police

Digital and social media provide many opportunities for people to easily engage and collaborate with peers, however, there are some people who misuse these opportunities. There is no clear distinction between the online and offline environments, particularly from the perspective of a young person, and those most vulnerable in the offline environment are also most often targeted online.

It is often those who are seen as “different” that are targeted by forms of online and mobile bullying, as well as traditional forms of bullying. The difference with cyberbullying is that it can be 24/7 and difficult for the young person to escape from. Other challenges which users must face online are privacy and reputation management. Once something goes online it can never be deleted, it is there forever. This requires users to think before they post as a photo or email shared carelessly can have negative impacts on their reputation or the protection of their private information.

Whilst any approaches to reducing the abuse of technology must be comprehensive, this presentation will focus on the steps that individuals and organisations can take to minimize their exposure to online risks.

SATURDAY 22 OCTOBER 2011

15:30-16:50

PLENARY 4 – Treatment and care – now and the future

Room: Freshwater 2 & 3

Chair: Geoff Simon

What are some of the issues?

Geoff Simon

Queensland Health Blood Management Program

Geoff Simon has worked in the Queensland Health Blood Management Program since 2007, initially as Scientific Advisor and currently as Director of the unit. After graduating from the Queensland University of Technology with a Bachelor of Applied Science in Medical Laboratory science, he worked initially in a range of pathology disciplines before moving into management roles in pathology laboratories. He has worked extensively in both the private and public sectors.

Geoff's interest in the field of blood transfusion and the supply, management and use of blood products has increased significantly since his appointment in January 2007 to lead a project to develop an on-line ordering and receipting system for blood and blood products. The "ORBS" system was designed and developed in house, was implemented across Queensland in 2008, and subsequently adopted as "BloodNet" in other Australian states and territories. Geoff is the jurisdictional representative on the Australian Bleeding Disorders Registry Steering Committee and is the Jurisdictional Blood Committee (JBC) member for Queensland.

Expectations from a community perspective

Deon York

Haemophilia Foundation of New Zealand

This session provides an overview of the bleeding disorders community's expectations in terms of the health care that they receive. The relationship between patients and the health systems that provide their care has changed dramatically. The shift from the patient as receiver of care to joint participant in decision-making and the idea of 'patient-as-consumer' reflects this change. With new patient rights come new expectations. Conversely, rights also carry responsibilities. How do bleeding disorders communities now engage with health services and what are the implications for the future?

Optimising supply and demand for clotting factors

Stephanie Gunn

National Blood Authority

Demand for clotting factors continues to increase and achieving the perfect balance in supply arrangements that best meet patient clinical needs in the context of financial pressures on the health sector is challenging. Factors that influence this balance and current strategies and options that are being explored to improve planning, modeling and efficiency within the sector will be discussed. But the challenge is also to ensure the right products are available and the process for assessing proposals for new products will be explained.

The future of haemophilia care – a personal view

Dr Mike Makris

Sheffield Haemophilia and Thrombosis Centre, United Kingdom

Predicting the future is not easy but this should not stop educated guesses at the subject for the near future! Pre-implantation genetic diagnosis and embryo selection is at its infancy but is likely to be more widely available and used by some families with known severe haemophilia. Prophylaxis is already the norm in childhood and will be the standard of care for adults as well. Most concentrates will be recombinant and will have longer half lives allowing less frequent administration. All products will still only be available for intravenous use. For patients with HIV infection, HAART will need to be continued for life and a disease eradication therapy will be unlikely. Triple therapy for hepatitis C will be the norm for the next 5 years and new therapies will be introduced allowing disease suppression for the minority who fail to clear the virus. New products are likely to become available for inhibitor eradication and treatment; although it will be easier to predict who will develop an inhibitor, complete prevention is unlikely to occur. Gene therapy will be more widely available but it will remain a research tool for at least the next 5-10 years because of concerns around long term safety. Haemophilia centres will be more centralised but patients will have to visit them less often with increasing use of telemedicine. Most care in haemophilia centres will be delivered by specialised nurses and management of co-morbidities and problems of old age will become more prominent. Within 10 years it is likely that the life-expectancy of a person born with haemophilia and who survives the first week of life, will exceed that of the normal population.

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