

15TH

Australian & New Zealand

HAEMOPHILIA CONFERENCE

Life Challenges 

Brisbane, 8-10 October 2009 www.haemophilia.org.au



Conference Handbook and Abstracts

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NATIONAL PATRON - MESSAGE

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

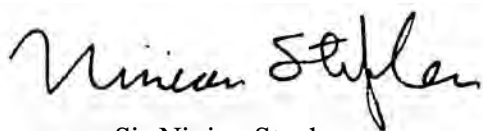


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Victoria Australia

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Email: ninian.stephen@pmc.gov.au

Welcome to the 15th Australian & New Zealand Haemophilia Conference hosted by Haemophilia Foundation Australia in Brisbane.

As the bleeding disorders communities of Australia and New Zealand come together for the 2009 conference I hope you will enjoy the opportunities for discussion and take home valuable information that will support you to meet your Life Challenges.



Sir Ninian Stephen
National Patron
Haemophilia Foundation Australia

WFH PRESIDENT – MESSAGE

WORLD FEDERATION OF
HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA
Treatment for All



Greetings from World Federation of Hemophilia and a warm welcome to the 15th Australian and New Zealand Haemophilia Conference in Brisbane. I am sure you will enjoy the opportunity to come together at the conference to share information and ideas about the care and treatment of people with bleeding disorders. Thanks to the support of HFA, HFNZ, and the many dedicated volunteers, each day we move one step closer to achieving our collective vision of Treatment for All.



Mark Skinner
President
World Federation of Hemophilia

WELCOME

We welcome you to the 15th Australian & New Zealand Haemophilia Conference in Brisbane.

We sincerely thank the Program Committee for bringing what we hope will be a very exciting and informative meeting to you. The hard work and professional commitment is greatly appreciated.

We hope you enjoy the conference, and find it a stimulating and informative meeting. We encourage you to participate actively to add to the richness of this exciting conference.

Gavin Finkelstein
President
Haemophilia Foundation Australia

Deon York
President
Haemophilia Foundation of New Zealand

Dr James Daly
Chair
Conference Program Committee

Program Committee

| | |
|-----------------------|--|
| Dr James Daly (Chair) | Haematologist, Royal Hobart Hospital |
| Dr Julie-Anne Bell | Haematologist, Waikato Hospital |
| Kelly Brady | Social Worker, Royal Children's Hospital, Brisbane |
| Paul Bonner | Community & Youth Representative |
| Belinda Burnett | CEO, Haemophilia Foundation of New Zealand |
| Sharon Caris | Executive Director, Haemophilia Foundation Australia |
| Peter Fogarty | Community Representative |
| Wendy Poulsen | Physiotherapist, Royal Children's Hospital, Brisbane |
| Dr Megan Sarson | Project Officer, Australian Haemophilia Centre Directors' Organisation |
| Maureen Spilsbury | Social Worker, Royal Brisbane & Women's Hospital |
| Beryl Zeissink | Nurse, Royal Brisbane & Women's Hospital |

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 Sebel King George Square
Cnr Ann and Roma Streets, Brisbane
P: 07 3229 9111

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 all delegates and speakers, please switch off, or set to silent, your mobile phones and pagers during all sessions. Do not answer your mobile until you have left the room.

Name Tags

Entrance to the Exhibition area and Conference venue will be limited to name tag holders only. If you misplace your name tag, please advise the staff at the Registration and Information Desk.

Personal Mail

The Conference Organisers will not accept responsibility for personal mail. Please have all mail sent to your accommodation address.

Business Centre

The business centre is on Level 4 of the Sebel Tower, and guests will require their room key to access the centre. Internet cards can be purchased from reception with the following charges: 1/2 hour - \$15.00 or 2 hours - \$26.00.

Registration and Information Desk

All enquiries should be directed to the Registration and Information Desk in the Grand Windsor Foyer (see attached venue map), which will be open at the times listed below.

| | |
|--------------------|-----------|
| Thursday 4 October | 1700-1930 |
| Friday 5 October | 0730-1730 |
| Saturday 6 October | 0730-1700 |

Haemophilia Treatment

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

Royal Brisbane & Women's Hospital
Queensland Haemophilia Centre
Level 4, West Block, Butterfield Street, Herston
Telephone 07 3636 5727 / 8760
Emergency 07 3636 8111 and page 59016

Royal Children's Hospital
Queensland Haemophilia Centre
Banksia Ward, Level 3 Woolworths Building, Herston Road, Herston
Telephone 07 3636 9030
Emergency 07 3636 8111 and page 42029

Childcare

Childcare is not available. Children are not permitted in Conference sessions.

SOCIAL PROGRAM

WELCOME & EXHIBITION OPENING

Thursday 8 October at 1830-1930
Grand Windsor Ballroom, The Sebel

Come along to our Welcome & Exhibition opening on Thursday evening. You will have the opportunity to see the Exhibition and meet people before the Conference. Free for all registered delegates.

REMEMBRANCE SERVICE

Friday 9 October at 1800-1830
Hillstone, St Lucia

The Remembrance Service is a time for people to come together and think of 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.

For people attending the service a bus will leave the front of the hotel at 1730 for Hillstone.

GALA DINNER

Friday 9 October at 1900-2300

The Gala Dinner will be held at Hillstone, St Lucia and is the highlight social evening for the Conference. Set in a relaxed atmosphere, the night will give you an opportunity to meet new friends and catch up with old ones!

Tickets must be pre-purchased. The Gala Dinner is a free seating event.

Transportation will leave at the following advertised times. If delegates miss the times, you will need to seek your own transport to the venue.

From hotel to Hillstone

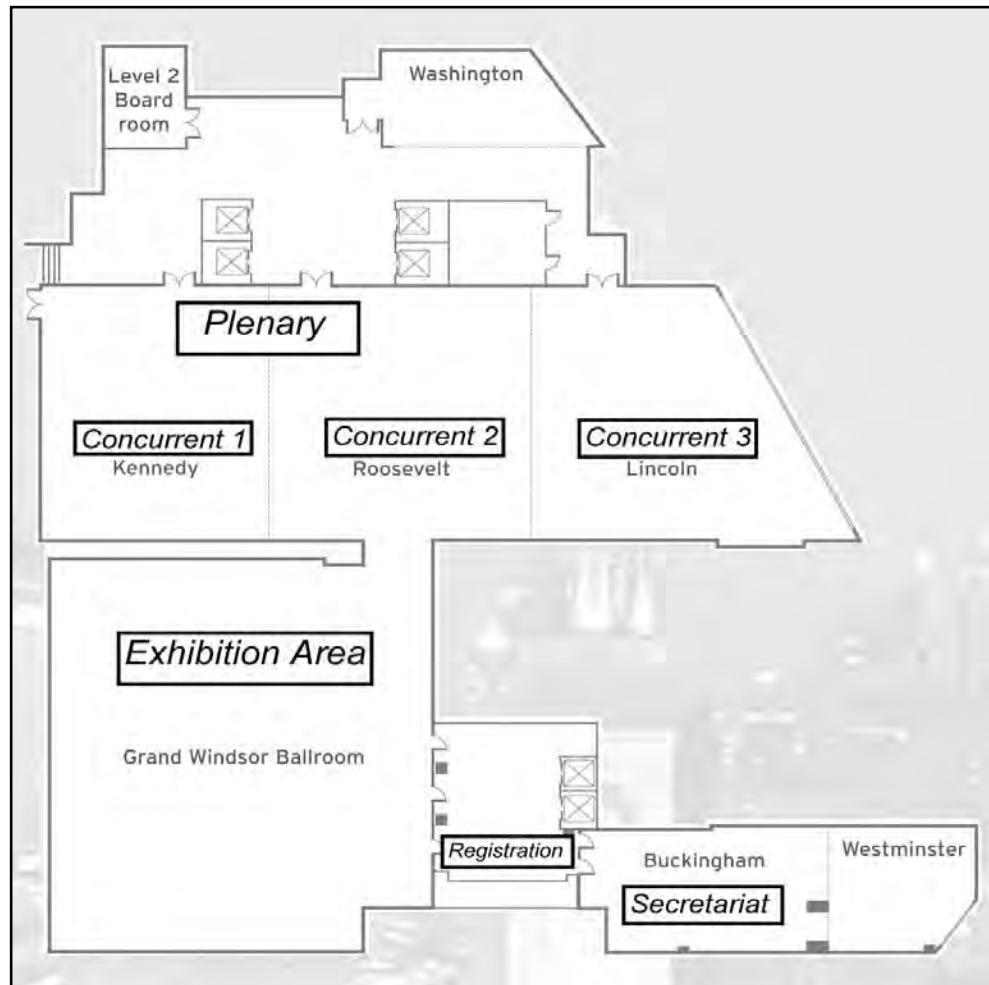
1st bus – 1800
2nd bus – 1830
3rd bus (if required) - 1900

From Hillstone to hotel

1st bus - 2215
2nd bus –2315

Transport ticket and Gala Dinner tickets will be in your welcome packs.

CONFERENCE VENUE MAP



EXHIBITION DIRECTORY

Baxter Healthcare Pty Ltd
Contact: Danielle Hunt
PO Box 88, Toongabbie, NSW 2146
P: 02 9848 1111

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: Wendy Thomas
Level 3, 21 Solent Circuit, Baulkham Hills, NSW 2153
P: 1800 668 626

Wyeth Australia Pty Ltd
Australia Contact: Monica Collins
New Zealand Contact: Warwick Jeffery
Locked Bag 5002, Baulkham Hills, NSW 2153
P: 02 8850 8200
Medical Information: 1800 500 498

Octapharma
Contact: Simon Sestich
Jones Bay Wharf, 42/26-32 Pirrama Rd, Pyrmont, NSW 2009
P: 02 8572 5800

Livewire.org.au
Contact: Rosa Gangemi
Level 2, 80 Chandos Street, St Leonards, NSW 2065
P: 02 8425 5926

Haemophilia Foundation Australia
Contact: Sharon Caris
1624 High Street, Glen Iris, VIC 3146
P: 03 9885 7800 Freecall: 1800 807 173

Haemophilia Foundation of New Zealand
Contact: Belinda Burnett
PO Box 16582, Hornby, Christchurch, NEW ZEALAND
P: +64 3 344 5204

CONFERENCE PROGRAM

THURSDAY 8 OCTOBER 2009

| | |
|-----------|--|
| 1230-1630 | Youth Activity Meet & Greet and Abseiling activity |
| 1830-1930 | Welcome and Exhibition Opening |

FRIDAY 9 OCTOBER 2009

| | | | |
|-----------|--|---|---|
| 0840-0900 | Official Welcome by HFA and HFNZ Presidents ~ Gavin Finkelstein and Deon York Room: Kennedy & Roosevelt | | |
| 0900-1030 | Plenary 1 Assessing the impact of chronic disease on adolescents - a practical psychological paradigm ~ Dr Michael Carr-Gregg Room: Kennedy & Roosevelt Chair: Maureen Spilsbury | | |
| 1030-1100 | MORNING TEA | | |
| 1100-1230 | Concurrent 1 Family factors: challenges & solutions Room: Kennedy Chair: Kelly Brady | Concurrent 2 Product safety Room: Roosevelt Chair: Rob Christie | Concurrent 3 von Willebrand Disorder Room: Lincoln Chair: Dr James Daly |
| | Parents Empowering Parents (PEP) ~ Anne Jackson, Sharon Hawkins, Cheryl Ellis Moving on: preparing for transition to adult life ~ Margaret Rae Venous access and ports ~ Helen Starosta | UK vCJD experience ~ Dr Paula Bolton-Maggs vCJD risk and product safety ~ Prof Albert Farrugia | AHCDO Guidelines ~ Dr James Daly Pathology and treatment ~ Dr Jeremy Robertson Living with VWD ~ Lorraine Bishop & Lauren Winders |
| 1230-1330 | LUNCH | | |
| 1330-1500 | Concurrent 1 Women's issues Room: Kennedy Chair: Belinda Burnett | Concurrent 2 Treatment and management of Inhibitors Room: Roosevelt Chair: Dr Chris Barnes | Concurrent 3 Haemophilia across the continuum Room: Lincoln Chair: Penny McCarthy |
| | Women's issues – an overview and introduction ~ Belinda Burnett My journey with haemophilia B ~ Justine Mamootil Menorrhagia, pregnancy and delivery ~ Dr Paula Bolton-Maggs Discussion | Codey's personal experience Risk factors for inhibitor development ~ Dr Simon Brown Caring for people with inhibitors ~ Dr Chris Barnes | Haemophilia – talking 'bout your generation ~ Penny McCarthy Maintaining health and independence, living with arthritis ~ Jann Anderssen Haemophilia and the added health benefits from general practice care ~ A/Prof Jane Smith Health issues for an ageing haemophilia population ~ Dr Huyen Tran Discussion |
| 1500-1530 | AFTERNOON TEA | | |
| 1530-1700 | Plenary 2 Good joints for a better life Room: Kennedy & Roosevelt Chair: Wendy Poulsen | | |
| | The benefits of physiotherapy - exercise & fitness, maintaining healthy joints, optimising prophylaxis ~ Kathy Mulder Understanding rheumatology - inflammatory processes, MRIs and radiosynovectomy ~ Dr David Kandiah Orthopaedic problems and solutions ~ Dr Brett Halliday Questions and discussion | | |
| 1800-1845 | Remembrance Service <i>Hillstone, St Lucia</i> | | |
| 1900-2300 | Gala Dinner (\$65 per person, tickets must be pre-purchased) <i>Hillstone St Lucia</i> | | |

SATURDAY 10 OCTOBER 2009

| | | | |
|-----------|---|---|--|
| 0730-0830 | Men's Breakfast (\$25 per person, tickets must be pre-purchased) Chair: Matthew Stewart Speaker: Steve Manning - "Fitness and its benefits" Room: Washington | | |
| 0730-0830 | Women's Breakfast (\$25 per person, tickets must be pre-purchased) Chair: Sharon Caris Speaker: Kathy Mulder - "Amazing Mothers" Room: Lincoln | | |
| 0900-1030 | Plenary 3 The importance of comprehensive care for patients, families, health professionals and the health care system - meeting the challenges Room: Kennedy & Roosevelt Chair: Kathy Mulder | | |
| | A perspective of a young family ~ Helen Fogarty A perspective of an adult with haemophilia ~ Mike O'Reilly Using clinical data, evidence and experience – the benefits of benchmarking ~ Dr Chris Barnes History of comprehensive care and current best practice ~ Dr John Rowell Physiotherapy - an overview ~ Debbie Thompson Nurse – an overview ~ Janine Furmedge Social Worker – an overview ~ Maureen Spilsbury Discussion | | |
| 1030-1100 | MORNING TEA | | |
| 1100-1230 | Concurrent 1 Understanding genetics and reproductive choices Room: Kennedy Chair: Dr John Rowell | Concurrent 2 Living with hepatitis C Room: Roosevelt Chair: Suzanne O'Callaghan | Concurrent 3 Free Papers Room: Lincoln Chair: Beryl Zeissink |
| | An overview of genetics ~ Dr John Rowell How genetic counselling can help ~ Katherine Rose Preimplantation genetic diagnosis and assisted reproductive technology in haemophilia ~ Dr Penelope Foster A carrier's journey ~ Jane Devlin Discussion | Personal reflections on living with hepatitis C, treatment and support ~ Mark Ivory Update on hep C, treatment, care and future directions ~ Dr Greg Dore Decisions about hepatitis C treatment and resilience during treatment ~ A/Prof Carla Treloar Dealing with your mental health - managing hep C symptoms and treatment ~ Dr Paul Pun Discussion | The HFNZ community needs assessment: preliminary findings, preliminary findings ~ Chantal Lauzon A retrospective audit of yttrium synovectomies at The Alfred ~ Dr Anne Powell The psoas muscle and sexual health ~ Matthew Stewart 30 years' experience of joint replacements in patients with bleeding disorders in SA ~ Dr Lay Tay Outcomes after joint arthroplasty or arthrodesis at an Australian Haemophilia Centre ~ Dr Kemble Wang Report of a survey of use of portacaths ~ Dr Susan Russell |
| 1230-1330 | LUNCH | | |
| 1330-1500 | Concurrent 1 Good dental care for adults and children with bleeding disorders Room: Kennedy Chair: Dr James Daly | Concurrent 2 Living with HIV Room: Roosevelt Chair: Alex Coombs | Concurrent 3 Practical Living Room: Lincoln Chair: Leonie Mudge |
| | Dental care & health in Adults ~ Dr Ian Hewson The Great Australian Bite ~ Dr Kerrod Hallett A personal experience ~ Paul Bonner Discussion | Psycho-social aspects of disclosure ~ Alex Coombs Personal reflections ~ Matt Powell HIV in 2009 means viral suppression for all. New opportunities and new challenges ~ Dr Mark Kelly Positively addressing personal barriers- lets talk about... sex, disclosure & relationships ~ Georgia Ash Discussion | Superannuation & insurance (Travel & income protection) ~ John Berrill Income support/financial assistance ~ Leonie Mudge Career and employment: challenges and choices panel ~ Mike Holloway, Luke Chipperfield, Robert McCabe Discussion |
| 1500-1530 | AFTERNOON TEA | | |
| 1530-1650 | Plenary 4 Haemophilia care and treatment- where have we come from, and where are we going? Room: Kennedy & Roosevelt Chair: Deon York | | |
| | History of haemophilia care, new treatments, treatment needs in the developing world ~ Dr Paula Bolton-Maggs Gene therapy for haemophilia: what's the holdup? ~ Prof John Rasko Trends in treatment product use and expenditure in Australia ~ Dr Alison Turner Ethics, cost and sustainability- the future horizon ~ Deon York Discussion | | |
| 1650-1700 | Closing remarks by HFA and HFNZ Presidents ~ Gavin Finkelstein and Deon York | | |

POSTER DISPLAY ABSTRACTS

The poster display will be in the Grand Windsor Ballroom with the exhibition. All posters will be displayed for the duration of the conference.

POSTER 1

Name: Ms Dilinie Herbert and Prof Paul Komesaroff

Co-authors: Prof Agnes Bankier, Prof Alison Street, Dr Chris Barnes and Dr Samantha Thomas

Institution/Organisation: Centre for Ethics in Medicine and Society, Monash University

Title of Abstract: The social and ethical dimensions of genetic testing: a longitudinal study of the haemophilia community

In Victoria subsidised genetic testing services are available for families with haemophilia following genetic counselling. We have been involved in an ongoing study of the attitudes and experiences of members of the haemophilia community in relation to genetic testing, some details of which have been previously reported. This presentation will explore further data from this study and provide an interpretative framework.

Our aim is to explore the interest in and uptake of genetic testing services within the haemophilia community. We have employed three methods of inquiry: qualitative interviews, community consultations and a quantitative questionnaire. We have documented people's experiences of genetic services longitudinally, before and after counselling and after testing in order to gain insight into how people negotiate decisions of particular importance to them.

Qualitative techniques have been used primarily to identify and map the main themes within this area of experience. A series of interview schedules were developed based on pilot research. Participation was invited from known people with haemophilia and carriers of the condition through counselling services and treatment centres. All interviews were recorded, transcribed and analysed using grounded theory techniques.

Sixty nine participants were interviewed. In general, participants expressed positive attitudes towards their experiences of haemophilia and were optimistic about genetic testing. They considered genetic counselling to be a useful source of information. However it rarely contributed to someone's decision to have genetic testing. Discussions about antenatal genetic testing revealed significant anxieties around family planning, with many women declining any form of testing during pregnancy.

Community consultation meetings help clarify the themes revealed in the interviews and will inform the quantitative questionnaire, which will be widely distributed in the coming months. It is anticipated that a full appreciation of individual narratives about predictive testing will contribute to enhanced services for the entire community.

POSTER 2

Name: Penny McCarthy

Institution/Organisation: The Alfred

Title of Abstract: New products, new practice

Historically, patients with haemophilia at this centre relied on empirical dosing for prophylaxis, demand therapy and surgery.

In July 2006 a choice of treatment products was introduced for all haemophilia patients. In response to the introduction of the new products, the decision was made by the centre that a limited pharmacokinetic study would be performed on the patients swapping to a newer product. Approximately 80 patients chose to swap from the Baxter product 'Recombinate' to either the Baxter product 'Advate' or the Wyeth product 'ReFacto'.

Prior to swapping, each patient had a pre-dose inhibitor screen and Factor FVIII level performed. Further FVIII levels were taken at one hour post dose and at twenty four hours post dose.

This has been a useful exercise. Recognising the benefits of this information has influenced us to change our practice and tailor the patients' prophylaxis, demand therapy and surgery treatment doses where possible; and in some cases there has been a reduction of FVIII use, a decrease in the frequency of prophylaxis infusions, and in 2 cases swapping to the alternate product

POSTER 3

Name: Megan Walsh

Institution/Organisation: Alfred Hospital

Title of Abstract: Product choice – what factors influence a patients decision?

In late 2004 in response to a shortage in Australian produced plasma derived factor VIII and lobbying from the haemophilia community, the Australian government decided to fund recombinant products for all haemophilia patients. Initially all were changed on to a first generation recombinant product Recombinate (Baxter). A second tender was negotiated last year by the National Blood Authority and patients have access not only to Recombinate but a second generation product Refacto (Wyeth) and a third generation product Advate (Baxter). This is the first time the Australian haemophilia population has had choice of product.

All patients have been offered the opportunity to swap to different products. Each patient was invited to the centre and shown a video on reconstitution for each of the new products; they were also offered a practice kit of each product to try. Of the patients on home therapy, both demand and prophylaxis, it appears equal numbers have decided to either remain on Recombinate or to swap to either Refacto or Advate.

It was decided to survey the home therapy patients in particular as they administer their own treatment to see what sort of factors influenced their change to a newer product and after now having the experience of swapping between 2 different recombinant products, would they continue to swap products as newer products come on to the market; or are there particular factors that guide their decision making, for example, diluent volume, ease of use, reconstitution devices, or larger dose vials sizes, or particular company loyalty?

The survey showed that smaller infusional volumes and dose corresponding to 1 vial were the most popular reasons for changing product. With the ease of reconstitution, smaller packaging and equipment supplied also assisting decision making.

POSTER 4

Name: Julia Ekert

Co-authors: Janine Furmedge, Chris Barnes

Institution/Organisation: Royal Children's Hospital Melbourne

Title of Abstract: Implementation of Home Therapy Home Delivery Program for patients at the RCH Melbourne

Outline

When the NBA tender for the supply of Blood and Blood products was decided in 2004-05 the haemophilia community was faced with the logistical problem of having more than one supplier of Recombinant factor VIII. Although a good result, this presented a problem with the home therapy supply system in operation at our hospital. All patients picked up their monthly clotting factor supplies at the hospital Blood Bank. The addition of another two brands of Recombinant factor VIII created storage and logistical problems for the blood bank. The Haemophilia Centre investigated utilising the pharmaceutical companies' home delivery programs in order to resolve some of these issues.

Description

A 6 month trial involving Wyeth and Baxter's home delivery program was conducted. HTC staff consulted with each pharmaceutical company to explore their home delivery programs and tailor them to haemophilia patients at our centre. During the trial period, there was no contact between the pharmaceutical company and patients. An unexpected benefit for the HTC has been a marked decrease in urgent requests for clotting factor due to regularly HTC staff contacted patients each month to do a clotting factor stocktake and then placed an order with the pharmaceutical company. After the 6 month trial period feedback from patients was very positive and home delivery was made available to all patients. Additional refinements were made to the process such as setting maximum stock levels and allowing the pharmaceutical company to contact patients for the monthly stocktake. All orders required approval from the HTC. After 12 months of home delivery families were asked to complete a satisfaction survey.

Conclusion

The result of the survey was overwhelmingly in favour of home delivery with patients and families stating that it had changed their quality of life for the better. An unexpected benefit for the HTC has been a marked decrease in urgent requests for clotting factor due to the introduction of monthly stock takes.

POSTER 5

Name: Penny McCarthy

Co-authors: Megan Walsh

Institution/Organisation: The Alfred

Title of Abstract: A two year review of the direct delivery program

Home treatment has been available to people with haemophilia for more than a decade. Following the Defined Blood Products deed of 2006, provision was made for the suppliers to directly supply the patient with Factor concentrates.

A decision was made to trial the direct delivery program with both Wyeth Australia Pty Ltd and Baxter Healthcare Pty Ltd in this centre.

Our review of the two home delivery services has demonstrated significant change in work practices hospital wide. The introduction of formalised delivery contracts with the patient and the use of multi-media communication has altered and improved the engagement between haemophilia nurses and people with haemophilia. Improved adherence to treatment plans has been noted as has the reduced number of hospital presentations, in and out of centre operating hours, due to 'running out of product'. The results of a patient satisfaction survey from our centre are discussed.

POSTER 6

Name: Megan Walsh

Institution/Organisation: Alfred Hospital

Title of Abstract: Vein health – is there a need for on going education

There is much information in the literature on managing difficult access issues in Haemophilia patients with the care of Intravenous access devices and arterio-venous fistulas being well documented. But there appears to be little on the maintenance of vein health in haemophilia patients. Prophylaxis regimes are now becoming more individualized with regimes ranging from daily to 2-3 times per week and most children beginning self access in their early teens. Many more patients are being maintained on prophylaxis well in to adulthood. On examination of patients coming in for review at the centre it has been found that some have severely scarred veins. Some only appear to be accessing one vein, while others who had been accessing their veins for a similar amount of time have perfect veins with little damage or scarring at all. Several elderly patients have lost their ability to self access due to permanent damage of the only vein they use. It was decided to survey the patients on

home therapy both those on demand and prophylaxis to determine what the patients knowledge was on maintaining good vein health and what, if anything, they did to promote this. It would also allow us to ascertain practices we could introduce to help them, for example arm exercises, vein training, trouble shooting tips to maintain long term self venous access, and whether structured educational material was required. The survey showed that many patients felt they had little knowledge on ways of promoting long term vein health. Patients felt educational material on maintaining vein health would be beneficial, especially if available in different formats. It demonstrated there also was a need for trouble shooting tips when patients were having problems and the need for more emphasis on vein rotation.

POSTER 7

Name: Katherine Angus

Co-authors: Beryl Zeissink, Raymond Chan

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

Title: Does self-cannulation education minimise venous access complications in patients with haemophilia receiving intravenous therapy at home? A systematic review.

Current management of haemophilia has improved clinical outcomes and quality of life through enabling prophylaxis and on-demand therapy to be self-administered in the home. Poor venous access and complications are barriers to home treatment. Therefore, effective self-cannulation techniques must be taught to patients and caregivers to reduce venous access complications before commencing home treatment. A systematic review of the literature was conducted to identify evidence about the effect of self-cannulation educational interventions on venous access complications.

The reviewers conducted searches of the following databases: The Cochrane Library, OVID Medline, OVID CINAHL, EBM reviews (OVID), PubMed, Johanna Briggs Institute of Evidence Based Medicine. The following search terms were used: haemophilia, hemophilia, bleeding disorders, coagulation disorders, peripheral venous access, venous access, cannulation, self-cannulation, self-administer, self-infusion, infusion, injection, self-injection, self-management, self-insertion, venipuncture, intravascular access, intravenous cannulation, teaching, education, learning, training, knowledge, techniques, patient education, practice, knowledge base, home therapy, home treatment, home administration, compliance, self efficacy, outcomes, complications, infection, thrombophlebitis

There is a lack of research investigating the effects of educational interventions on venous access complications in patients with haemophilia. A specific educational intervention for teaching cannulation techniques to haemophilia patients needs to be developed to enable research to be conducted in this area.

For children and young adults with haemophilia, further research needs to be undertaken in order to identify:

- The most appropriate time to teach self-cannulation techniques
- Learning needs relating to self-cannulation
- The most effective patient teaching methods.

POSTER 8

Name: Fiona Lyon

Co-authors: None

Institution/Organisation: Private Practice

Title of Abstract: Getting older, living at home - pre-factor 8. A case study about home access and maintenance of personal independence in a rural area.

Few occupational therapists get to work with 'older' people with bleeding disorders in rural NSW. Whilst medical information is readily shared between doctors, few allied health experts from the major clinics get to visit their client's homes in remote communities to apply practical, functional support.

This case study aims to review some of the functional problems of an aging client (born pre-factor 8) and the challenges in mobility and increasing difficulties with activities of daily living whilst living alone in a rural community.

Starting from a blank page of specific clinical experience with haemophilia, this occupational therapist embarked upon assessment, problem solving, prescription, negotiation, networking and connecting with community resources.

The role of equipment prescription for joint preservation, overcoming restricted ranges of movement, inactivity, pain management and oedema control will also be addressed in the presentation.

Support of both government agencies, local service clubs and Haemophilia Foundation Australia was critical to the supply of equipment and modification of home access for ongoing independence at home. Working together with these agencies has proven to make a significant difference to the quality of life on one individual and significantly avoiding his premature institutional care.

'Before' and 'after' photos of the modified home as well as pictures of equipment will be included in the presentation.

POSTER 9

Name: Anne Powell

Co-authors: Penny McCarthy, Megan Walsh, Alison Street

Institution/Organisation: Alfred Hospital, Melbourne

Title of Abstract: The role of a rheumatologist in a haemophilia centre

The current focus in the treatment of haemophilia is shifting towards chronic disease management due to improvements in both mortality and morbidity. Haemophilic arthropathy is increasingly a major issue in ongoing care, leading to greater input by rheumatologists into the multidisciplinary clinics.

Prompt treatment of target joints and recurrent bleeds is critical in reducing joint damage. The use of treatments including simple analgesics, cortisone injections and yttrium synovectomies is discussed. The management of endstage arthropathy is important, particularly as joint replacement is often contemplated at a relatively young age.

Increasingly, musculoskeletal issues not specific to a bleeding disorder are being misdiagnosed as potential target joints and treated with prophylaxis with no effect. A large percentage of current clinic reviews involve the diagnosis and management of soft tissue injuries which are not directly related to haemophilia. There has also been a small number of patients with hepatitis C related inflammatory arthritis which often has a delayed diagnosis due to the assumption that the joint pain was due to recurrent bleeds.

In conclusion, there is an increasing role for a rheumatologist in a haemophilia centre to actively treat haemophilic arthropathy, but also to diagnose and treat other rheumatological conditions that may still affect our patient population.

POSTER 10

Name: Beryl Zeissink

Co-authors: Kate Angus, Dr John Rowell

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

Title of Abstract: A snapshot of surgery in Queensland

In a majority of cases, people with haemophilia or other inherited bleeding disorders will experience excessive bleeding following surgery if untreated or inadequately treated with factor replacement therapy. The severity of haemophilia, the factor level and type of surgery will determine the extent of bleeding and complications that can develop. With many advances in surgery plus an aging population, a growing number of surgeries and more complicated surgeries are being performed in patients with haemophilia. Most surgery is planned; however some surgeries occur under emergency circumstances. The expected outcome of any surgery is to extend life or relieve symptoms.

This poster will look at a “Snapshot of surgery in Queensland”. This will include, types of surgeries performed, patient diagnoses and processes involved in the planning for surgery. A major role of the Haemophilia team is to liaise with the surgeon, anesthetist, and multidisciplinary team to optimise patient outcomes. This practice will also be explored.

POSTER 11

Name: BJ Ramsay

Co-authors: Prof. John Carter, Dr Julia Phillips

Institution/Organisation: Wellington Regional Hospital,
Haemophilia department

Title of Abstract: Haemophilia and Cox 2 (cyclooxygenase 2) selective NSAIDs (non-steroidal anti-inflammatory drugs): an experience

Within the haemophilia population the use of traditional non-selective NSAIDs, which reduce pain and stiffness in haemophilic arthropathy, have been relatively contraindicated due to their “aspirin like” anti-platelet effect and risk of gastric irritation. Over recent years improvements in treatments and improved understanding of the inflammatory processes in haemophilic joints has seen some treaters introduce the cautious use of NSAIDs as an extra resource in their management of haemophilia patients. A new generation of COX-2 selective NSAIDs do not affect platelet function and cause less gastrointestinal bleeding problems, therefore seem ideally suited to the haemophilia patient with arthropathy.

We report on the use of a COX-2 NSAID (Celecoxib) in a 63 year old man with severe haemophilia B and extensive arthropathy who is a patient of the Wellington Haemophilia Centre. The patient recorded a 32% reduction in factor usage in the first 3 months of Celecoxib usage compared to previous 3 months. Also the use of Celecoxib was associated with both symptomatic benefits and reduced analgesia usage. No adverse effects were reported. The use of Celecoxib in this patient has led to beneficial effects in quality of life, perceptions of bleeding, factor usage and has shown associated cost savings.

POSTER 12

Name: Andrew Atkins

Co-authors: Dr Lay Tay, Dr Simon McRae, Anne Till

Institution/Organisation: Royal Adelaide Hospital

Title of Abstract: Snapshot of haemophilia A patients with hepatitis C in South Australia

Hepatitis C is the most common transfusion transmitted viral infection seen in patients with bleeding disorders who were treated with plasma-derived blood products prior to 1990. Many patients and their families are now dealing with the consequences of chronic liver infection; of the six patients with haemophilia and hepatitis C who have died in the last 36 months, five of the deaths were directly related to their liver disease.

Our adult treatment centre has 131 haemophilia A patients, of which 85 have tested hepatitis C antibody positive. We recently conducted a hepatitis C update to determine more closely the needs of our patients.

Of the 85 adults that are hepatitis C antibody positive, 37 have cleared the virus, with more than half of these (20) doing so without treatment. Some 34 patients have been treated, with 17 achieving a sustained viral response. The other 17 patients failed therapy, due to poor or no response, relapse after therapy, or complications of side effects, and are now being monitored. Three patients are currently on therapy, with another five planning to commence. Three patients' current status is unknown. Of the remaining 20 patients who have not received treatment, eight are yet to have an initial hepatology consult (median age=38 years), seven are considered by their hepatologists to be inappropriate for treatment, and two have declined treatment. The genotype of 13 patients is unknown, with only three of these ineligible for treatment.

It is crucial that this patient group is educated and aware of treatment potential and the importance of looking after their liver health. Obstacles to achieving this were found to be distance and poor compliance. These barriers need to be overcome to give all patients the opportunity for surveillance and effective early treatment before liver damage occurs.

POSTER 13

Name: Silvana Gaudieri

Co-authors: Katja Pfafferott, Ross Baker, Maria Baccala, Susan Herrmann, Michaela Lucas

Institution/Organisation: Centre for Clinical Immunology and Biomedical Statistics, Royal Perth Hospital and Murdoch University

Title of Abstract: Host immune responses to the hepatitis C virus reflect outcome following multiple exposures to the virus and can inform vaccine design

Background: Individuals with haemophilia who were exposed to the hepatitis C virus (HCV) via contaminated blood products prior to screening in Australia showed divergent infection outcomes from clearance to chronic infection. These individuals were likely to have been exposed to multiple HCV strains, including the major circulating HCV genotypes 1 and 3. Individuals that remain HCV-RNA-negative despite multiple HCV exposures will demonstrate the signature of a successful multi-genotype response. Individuals that develop chronic infection may have successfully suppressed at least one genotype but be chronically infected with another. Studies have shown that the major determinants of outcome following infection with HCV are the host's T-cell immune responses and viral escape from these responses. However, there is limited overlap in the immune targets within the HCV genotype 1 and 3 genomes. This suggests that the immune targets within HCV selected by the host will influence infection outcome following multiple HCV exposure.

Methods: Blood collection and host genetic typing from 62 individuals with haemophilia from the Western Australia Haemophilia Centre (32 chronic, 30 resolved infection). Viral sequence was obtained (where possible). Individuals were screened using individualised IFN-gamma ELISpot assays to detect T-cell responses against genotype 1 and 3 peptides.

Results: Individuals who are chronically infected with HCV genotype 1 or 3 show responses to peptides of an alternate genotype. These results suggest that many of the immune responses we detect in individuals with chronic infection will be against those genotypes these individuals have previously cleared, implying that these responses may not be sufficient to provide protection against another HCV genotype.

Conclusions: The identification and analysis of T-cell responses in individuals with multiple exposures to HCV will provide critical insights for the development of therapeutic strategies to combat HCV infection, including an effective vaccine directed against the primary circulating HCV genotypes in Australia.

POSTER 14

Name: Suzanne O'Callaghan

Co-authors: Sharon Caris

Institution/Organisation: Haemophilia Foundation Australia

Title of Abstract: "A double whammy": living with a bleeding disorder and hepatitis C

Haemophilia Foundation Australia (HFA) recently undertook a national needs assessment to better understand the impact of hepatitis C on the bleeding disorders community. Most people with bleeding disorders who were treated with plasma-derived clotting factor concentrates were exposed to hepatitis C virus (HCV) before these products were inactivated for hepatitis C. Many have now been living with hepatitis C for more than 20 years.

Methods

- HFA member survey (2003)
- Focus groups with affected community members (2007-8)
- Community and health professional consultation (2006-8).

Results

Some people did not have hepatitis C symptoms and felt it was not affecting them. Most felt chronically unwell, and experienced fatigue, depression, liver pain, nausea and "brain fog". Hepatitis C was an extra burden on top of joint pain, illness and disability caused by haemophilia and, for some, co-infection with HIV. Many found their level of disability unmanageable by the age of 40 years, which impacted on their ability to work and their financial situation, home and social lives. Overload with health problems and health services was common. Many showed little understanding of their current hepatitis C or liver

health status or felt it was not a priority. This concerned health professionals and Haemophilia Foundations, with recent reports of serious liver disease and death among affected people. Treatment experiences varied: some were successful, many others had unsuccessful interferon monotherapy treatment in the early 1990s; some had difficulty accessing monitoring and treatment. Anger about their route of infection caused some to distrust the medical system. Fearing discrimination, most were wary of disclosing their hepatitis C status, increasing their isolation. Concerns about privacy and discrimination increased the complexity of linking individuals to mainstream welfare and support services as well as developing peer support programs.

Conclusions

Acquiring hepatitis C has had a profound impact on the health and welfare of the affected bleeding disorders community in Australia. Responding to the complexity of these issues is a challenge for HFA and involves a multidimensional strategy.

DISCUSSION WITH POSTER AUTHORS

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

| Friday 9 October 1300-1315 | Saturday 10 October 1300-1315 |
|--|--|
| <p>Poster 1 Ms Dilinie Herbert and Prof Paul Komesaroff <i>The social and ethical dimensions of genetic testing: a longitudinal study of the haemophilia community</i></p> | <p>Poster 2 Penny McCarthy <i>New products, new practice</i></p> |
| <p>Poster 7 Katherine Angus Does self-cannulation education minimise venous access complications in patients with haemophilia receiving intravenous therapy at home? A systematic review.</p> | <p>Poster 3 Megan Walsh <i>Product choice – what factors influence a patient's decision?</i></p> |
| <p>Poster 8 Fiona Lyon <i>Getting older, living at home - pre-factor 8. A case study about home access and maintenance of personal independence in a rural area</i></p> | <p>Poster 4 Julia Ekert <i>Implementation of Home Therapy Home Delivery Program for patients at the RCH Melbourne</i></p> |
| <p>Poster 10 Beryl Zeissink A snapshot of surgery in Queensland</p> | <p>Poster 5 Penny McCarthy <i>A two year review of the direct delivery program</i></p> |
| <p>Poster 6 Megan Walsh <i>Vein health – is there a need for on going education</i></p> | <p>Poster 14 Suzanne O'Callaghan <i>"A double whammy": living with a bleeding disorder and hepatitis C</i></p> |
| <p>Poster 9 Anne Powell <i>The role of a rheumatologist in a haemophilia centre</i></p> | <p>Poster 13 Silvana Gaudieri <i>Host immune responses to the hepatitis C virus reflect outcome following multiple exposures to the virus and can inform vaccine design</i></p> |
| <p>Poster 11 BJ Ramsay <i>Haemophilia and Cox 2 (cyclooxygenase 2) selective NSAIDs (non-steroidal anti-inflammatory drugs): an experience</i></p> | <p>Poster 12 Andrew Atkins <i>Snapshot of hemophilia A patients with hepatitis C in South Australia</i></p> |

FRIDAY 9 OCTOBER 2009

1100-1230

CONCURRENT 1 – FAMILY FACTORS: CHALLENGES & SOLUTIONS

Room: Kennedy

Chair: Kelly Brady

Royal Brisbane & Women's Hospital

“PEP Talk” – Health professionals and parents working together to help families successfully live with the challenges of a bleeding disorder

Sharon Hawkins, Haemophilia Centre of Western Australia; Anne Jackson, Women's and Children's Hospital SA; Cheryl Ellis, VIC

Parents of children with an inherited bleeding disorder can struggle with the knowledge they need to acquire to manage their child's bleeding disorder while also dealing with normal developmental stages and developing their parenting skills. At the time of diagnosis all the information can be overwhelming and for many parents the normal stresses of bringing up a child are heightened by the diagnosis of a bleeding disorder. Support from health professionals and peers throughout the developmental stages are essential to assist families to manage their child's care. A valuable addition to this support is a parenting program specifically adapted for parents of children with inherited bleeding disorders from 0-11 years old.

Parents Empowering Parents (PEP) has been offered in the United States for over a decade. In 2007, Haemophilia Foundation Australia (HFA) and Haemophilia Foundation New Zealand enabled Social Workers, Counsellors, Outreach Workers and selected parents from Australia and New Zealand to attend a train the trainer program for PEP.

In 2009, HFA sought funding for a pilot PEP to be rolled out in Western Australia. A collaboration between Paediatric Haemophilia Treatment Centres in WA and SA together with parent facilitators resulted in a PEP workshop. This team approach combined the strengths of peer support with professional expertise.

The goals of the PEP workshop were to increase the parent's knowledge in relation to: their child's bleeding disorder and how to manage bleeding episodes, child development, communication strategies, behaviour management skills, capacity to build self esteem and confidence, parenting skills, peer support and therapeutic relationships.

An evaluation of the PEP workshop was conducted and is being utilised to provide further improvements and opportunities for families to benefit from the collaboration.

Moving on: preparing for transition to adult life

Margaret Rae

Queensland Paediatric Rehabilitation Service

For young people with chronic medical conditions and disabilities and their families, the transition to adult life can be daunting. The preparation needs to start at a young age with families and the young person themselves learning to manage their condition. This presentation will address transition to adult medical, vocational and support services as well as how paediatric services can facilitate the development of age appropriate psycho-social and independence skills from a young age. The challenges of the teenage years will be discussed.

Venous Access and Ports

Helen Starosta

Royal Hobart Hospital, TAS

This presentation covers the current situation of venous access including Infusaports in the paediatric population. This will include interviews with families, families and children actually performing the procedures in the home setting and how they feel about different issues related to venous access.

FRIDAY 9 OCTOBER 2009

1100-1230

CONCURRENT 2 – PRODUCT SAFETY

Room: Roosevelt

Chair: Rob Christie

WFH Vice President, Finance

UK vCJD experience

Dr Paula Bolton-Maggs

Manchester Royal Infirmary, Manchester UK

In the 1980s an epidemic of BSE occurred in cattle in the UK followed by the identification of a new type of degenerative brain disease, variant Creutzfeldt Jacob Disease, in humans. This is characterized by occurrence in younger people, a longer duration and wider distribution of the causative agent, the prion, in body tissues including lymph nodes and spleen as well as the brain (rather than the brain alone as in sporadic CJD). Evidence suggests that the agent causing vCJD is the same as BSE and is acquired by eating infected food. While the total number of cases is small (168 in a population of over 60 million) and the number diagnosed each year falling, suggesting the CJD ‘epidemic’ may be ending, there is evidence that this disease may be transmitted by blood transfusion and also by factor products sourced from UK plasma between 1980 and 2001. No cases of vCJD have been reported in haemophiliacs, but one haemophiliac (reported February 2009) who died of unrelated causes was found to have the agent in his spleen but never manifested any evidence of the disease. All patients who might have received contaminated products have been informed, and several measures have been introduced to improve transfusion safety.

vCJD risk & Product Safety

Prof Albert Farrugia

Plasma Protein Therapeutics Association

The safety of concentrates for the treatment of haemophilia hinges on the selection of safe starting materials, the testing of such materials to exclude contaminating pathogens and the inclusion of pathogen eliminating steps in the manufacture. Of these elements, the use of pathogen elimination steps is the most important. These principles are similar irrespective of the source of the starting material – plasma or cell culture fluid – or the type of pathogen – viruses and prions. In this presentation, these principles will be described as they apply to the minimization of risk of vCJD, and the ways in which this was achieved in Australia over the past decade are discussed.

FRIDAY 9 OCTOBER 2009

1100-1230

CONCURRENT 3 – VON WILLEBRAND DISORDER

Room: Lincoln

Chair: Dr James Daly

Royal Hobart Hospital, TAS

AHCDO Guidelines

Dr James Daly

Royal Hobart Hospital, TAS

The members of the Australian Haemophilia Centre Directors' Organisation (AHCDO) met in Melbourne in October 2008 to initiate the development of consensus Guidelines for the Management of Von Willebrand Disease. In this session I will present the current status of these guidelines.

Pathology and Treatment

Dr Jeremy Robertson

Royal Children's Hospital & Pathology Queensland Central Laboratory

In 1926 Dr Erik von Willebrand published a complete description of a previously uncharacterised inherited bleeding disorder based on his careful investigation of a 6 year old girl and her extended family. He recognised that it was distinct from classical haemophilia, and the common condition now bears his name. Scientific advances during the second half of the twentieth century allowed discovery of the defective protein (von Willebrand factor), elucidation of its central role in primary haemostasis, and ultimately a clear understanding of the genetic basis and insight into the marked clinical heterogeneity of the disorder. Current treatment includes both specific and non-specific agents, with the prospect of recombinant products looming ever-closer.

Living with VWD

Lorraine Porter-Bishop

NZ

After many false starts, our son was diagnosed with severe von Willebrand disorder (VWD) Type 3. Now 12 years old, our son and family have already faced a number of trials with treatment and target joints. This presentation will describe the more recent part of our journey, which includes a radiosynovectomy, surgical arthroscopic synovectomy on our son's ankle, prophylaxis and the challenges and triumphs of finding suitable and engaging activities. The effect of being labeled with a 'disease' at school and with peers will also be discussed and ultimately how we have remained positive in trying to ensure the best quality of life for our son.

Lauren Winders

QLD

I was diagnosed with VWD at age two. This is a snapshot of what it's like to live with VWD.

Discussion Points

- The day to day challenges and issues including specific examples of its impact on daily activities
- The implications of VWD when having minor and major surgery and some tips on how to best transition through this period
- Utilising your medical team and VWD resources
- Taking responsibility for your own health.

FRIDAY 9 OCTOBER 2009

1330-1500

CONCURRENT 1 – WOMEN'S ISSUES

Room: Kennedy

Chair: Belinda Burnett

Haemophilia Foundation of New Zealand

Women's issues – an overview and introduction

Belinda Burnett

Haemophilia Foundation of New Zealand

I first became aware of haemophilia when my eldest daughter was diagnosed with moderate haemophilia A with a level of 2%. At the time, 20 years ago, there was no forum to discuss women's issues within the haemophilia community and the impact bleeding disorders had on their lives. Feeling isolated and uninformed, I made it my business to learn as much as I could about haemophilia but much of the information I found was old, outdated, and sometimes just incorrect!

In the past 20 years I have been to many conferences and spoken to many women about their bleeding issues. New Zealand, United Kingdom, Australia and United States of America have each developed programs that deal specifically with women's issues. Now there is information available for those who want it regarding the special issues that concern women and bleeding disorders. Knowledge is power, the more we learn, the more we can cope.

My journey with haemophilia B

Justine Mamootil

TAS

Haemophilia has always been considered as a male gene disorder but with better research and understanding we now know that women can not only be carriers but also sufferers of haemophilia.

Justine was diagnosed with mild haemophilia B Factor 9 deficiency at the age of 10. Throughout Justine's life, she has had to make choices, whether to have a child with haemophilia, bearing children and requiring treatment. This has given her many valuable experiences which she wishes to share. Justine has also been through some difficult challenges in growing up and in particular her challenge as a woman with menorrhagia.

For many women who carry the haemophilia gene, their sons have always been their priority and through Justine's gentle encouragement, many women have made their first step of getting a referral to a Haemophilia Treatment Centre to ensure their own health needs are met.

Today Justine would like to share with you her journey as a woman with haemophilia B.

Menorrhagia, pregnancy and delivery

Dr Paula Bolton Maggs

Manchester Royal Infirmary, Manchester UK

Haemophilia carriers, women with von Willebrand disease and those with rare bleeding disorders are at risk of excessive bleeding. Menorrhagia is very common and in the past has been an under-recognised source of poor quality of life. There are several helpful ways to document and manage this troublesome problem, particularly with various forms of hormone treatment. Women with more severe vWd and rare disorders may have additional problems with bleeding from ovarian cysts. These issues are being drawn to the attention of gynaecologists so that diagnosis is made in a timely manner. Carriers for bleeding disorders need to be identified so that they can be appropriately counseled and make their own reproductive choices. There are often many issues for carrier women, especially their feelings of guilt, and cultural issues must be sensitively managed. The family experience in the past may have a profound influence. Women with bleeding disorders or who are carriers of a possibly or known affected baby need careful planning for delivery with a team approach. This should include obstetrician, paediatrician and haematologist. The delivery plan should be written and a copy supplied to all involved medical attendants and the mother. The plan will detail how the mother with a bleeding disorder is to be managed, including prior discussion of pain management as epidural anaesthesia may not be possible, and the precautions required minimizing the risk of trauma to the baby. The rare disorders mostly are inherited as autosomal recessive conditions and are more common in racial groups where cousin marriage is common.

FRIDAY 9 OCTOBER 2009

1330-1500

**CONCURRENT 2 – TREATMENT AND MANAGEMENT OF
INHIBITORS**

Room: Roosevelt

Chair: Dr Chris Barnes

Royal Children's Hospital, Melbourne, VIC

Codey's Personal Experience

Codey

VIC

My name is Codey and I am 14 years old and was diagnosed with haemophilia B at 7 months and developed an inhibitor when I was 1 - and that's when my life changed.

I started getting bleeds into my right knee and ankle when I started to get active which my mum said was a nightmare as there many nightly trips to the hospital.

At the age of 1 ½ I went to the ICU and had my blood filtrated and a very high dose of factor IX each day which meant coming into hospital every day for 3 months.

In grade 5 Dr Chris Barnes spoke to me about trying chemotherapy to try and lower my immune system so I would not have an inhibitor or reaction to factor IX. This worked for many months and in that time I also had a halo put on my right leg to help it get straighten which was a success but a few months later I had a reaction to the factor IX at home. It was very scary for my mum and dad and extremely scary for me as I could not breathe. Once the ambulance got here it was a huge relief for me.

The worst thing about having haemophilia is that I miss out on so much school and also hanging out with my friends, and being in a wheelchair when I can't walk and also the pain that I am in most days. The best thing about having haemophilia is that the girls love me and that my family gives into me because I am spoilt rotten.

The next challenge for me is to have a procedure on my right leg which the doctor have not figured what they are going to do yet. Hopefully it will give me a better quality of life.

Risk factors for inhibitor development

Dr Simon Brown

Haemophilia Centre, Royal Children's Hospital, Brisbane, Queensland.

The development of inhibitors to treatment with factor concentrates remains the most significant complication for individuals with haemophilia. The development of inhibitors is associated with increased deterioration of joint function and has a major impact on the individuals affected and their families. Over the last decade, our knowledge of factors that contribute to an increased risk of inhibitor development has increased significantly. In particular the contribution of inherited factors, such as the underlying factor VIII gene defect, will begin to allow an assessment of an individual's risk of inhibitor development. However, many of the identified risk factors are not amenable to an intervention that may reduce the risk of inhibitor development. Some risk factors that are potentially amenable to manipulation, e.g. the type of factor VIII concentrate, remain contentious and there is an urgent need for further studies to address these issues.

Caring for people with inhibitors

Dr Chris Barnes

Royal Children's Hospital, Melbourne, VIC

The development of inhibitors remains the most important and feared complication affecting the management of young patients with haemophilia. Fortunately, the development of inhibitors is uncommon with modern management of patients with bleeding disorders and the early institution of prophylaxis likely having a major impact on the reduced incidence of inhibitor development. Initiation of immune tolerance remains the cornerstone of treatment but prophylaxis with bypassing agents is also becoming more regularly available. A number of international studies are ongoing and aim to address the optimal management of these patients but, in general, there is an absence of well established and widely accepted treatment protocols. In Australia, a major benefit of having limited treatment centers care for patients with haemophilia allows close collaboration and development of a forum for the discussion of difficult treatment decisions regarding the management of patients with inhibitors; the Tolerisation Advisory Committee (TAC) has been created with this purpose. The current presentation will review treatment options for patients with inhibitors and discuss the challenges and advantages of managing these patients in an Australian environment.

FRIDAY 9 OCTOBER 2009

1330-1500

CONCURRENT 3 – HAEMOPHILIA ACROSS THE CONTINUUM

Room: Lincoln

Chair: Penny McCarthy

The Alfred, Melbourne, VIC

Haemophilia – talking 'bout your generation

Penny McCarthy

The Alfred, Melbourne, VIC

This presentation is a short introduction to set the scene for 'haemophilia across the continuum' Baby boomers to Gen Y and beyond. It looks at the various generational milestones a person with haemophilia can experience and some of the associated issues that can arise.

Maintaining health and independence, living with arthritis

Jann Anderssen

Arthritis Queensland

Chronic Diseases are shaping up as one of the greatest challenges in the 21st century. They currently consume approximately 70% of the healthcare funds. A major implication of this trend is that health services must change in order to adapt to the growing number of people who currently have or will have a chronic disease.

There is clear evidence that learning the skills to self manage assists people to lead active and emotionally satisfying lives as well as reducing health care costs.

Effective self management is based on a partnership between the person with the disease, their families and health professionals in which they are encouraged to play an active role in managing the impact of the illness on their lives.

Through the development of adaptive strategies the individual is empowered to manage the signs and symptoms of their illness as well as cope with the impact of the illness on their lifestyle, emotions and relationships.

The most appropriate theoretical frame work for encouraging self-management involves the use of the client centred approach that is generic in nature rather than disease focussed, together with the use of goal setting and informed decision making.

Arthritis Qld has been successfully running the Lorig model, self- management courses since 1987. The key to their success is the use of various strategies to enhance self-efficacy and participation.

This presentation is directed towards providing a background and framework for both health professionals and consumers to encourage a greater self-management approach.

Haemophilia and the added health benefits from general practice care

A/Prof Jane Smith

Honorary Secretary RACGP and Chair, Queensland Faculty RACGP

Having a serious chronic disease like haemophilia does not make you immune to developing other diseases (the exception being a 1/3 reduced risk of ischaemic heart disease).

Unfortunately the law of averages dictates that we are all as likely as each other to develop an assortment of chronic diseases as we age.

The success of modern haemophilia treatment regimes means that having haemophilia will not prevent aging by causing an early death, in fact median life expectancy is cited as 75 years in moderate cases and 63 years in severe cases (who have escaped HIV infection). Even those infected by HIV and Hep C viruses now have much better treatment options and outlooks.

Getting older means getting more wear and tear and chronic diseases. General practitioners provide the majority of care for the most common conditions, such as diabetes, hypertension, other cardiovascular problems, cholesterol disorders, osteoarthritis and depression. They also provide or advise about most of the preventative care for chronic diseases such as immunisations, screening for bowel, breast, and cervical cancer.

For the long term benefit of the ageing haemophiliac, it is time for the long-term health care of haemophilia to include general practice as well as their other specialist care

Health issues for an ageing haemophilia population

Dr Huyen Tran

The Alfred Hospital, Melbourne, VIC

The availability of clotting factor concentrate over the last several decades, its utility as prophylaxis, and improved medical care provided by specialized haemophilia treatment centres have resulted in an increase the life expectancy of patients with haemophilia to greater than 70 years. Excluding patients infected with human immunodeficiency virus (HIV) and hepatitis C virus, patients with mild and moderate haemophilia now expect to live just as long as males in the general population, while the life expectancy among those with severe haemophilia continues to improve. Overall, the proportion of patients with haemophilia aged greater than 40 years is increasing.

“Older” patients with haemophilia have to endure both haemophilia-related health problems such as arthropathy and inhibitor development, and ageing-related ailments such as cancer and cardiovascular disease. The presentation will focus on the health issues facing an ageing haemophilia population.

FRIDAY 9 OCTOBER 2009

1530-1700

PLENARY 3 – GOOD JOINTS FOR A BETTER LIFE

Room: Kennedy & Roosevelt

Chair: Wendy Poulson

Royal Children's Hospital, Brisbane

The benefits of physiotherapy: exercise and fitness, maintaining healthy joints, optimizing prophylaxis

Kathy Mulder

Children's Hospital, Winnipeg, Canada

When clotting factor concentrates and factor prophylaxis became available, many people in the developed world believed that hemophilic arthropathy was going to be seen only in countries without adequate factor. In fact, hemophilic arthropathy continues to develop even in countries where factor prophylaxis is routine. Why is this? Using recent research from animal experiments, this presentation will describe how blood affects joints in the short and long term and will describe the importance of preventing bleeding. Clotting factor alone is not enough. Joint protection, activity selection, maintaining a healthy body weight and adequate rehabilitation of each and every bleed can optimize the assistance provided by expensive factor prophylaxis programs.

What can the physiotherapist do to help you? What can you do to help the physiotherapist?

Understanding rheumatology-inflammatory processes, MRIs and radiosynovectomy relevant to haemophiliac patients

Dr David Kandiah

Royal Brisbane and Women's Hospital & University of Queensland

Patients with haemophilia are known to have recurrent haemarthroses that can lead to rapid joint degeneration. The current advances in treatment of the factor deficiencies have reduced the occurrence of these haemarthroses. However the situation can still arise in some patients. We also still have to deal with the population of patients who have had haemophilia for some time before factor replacement therapy became extensively available. Patients with haemophilia can also develop other musculoskeletal conditions and do not always have to have bleeding related joint and soft tissue problems. This talk will include medical treatment options for musculoskeletal problems in patients with haemophilia. Case studies will be used to illustrate options of treatment for patients. MRI scans of joints have made a difference in allowing doctors to provide the best advice for patients regarding medical or surgical treatment based on the internal images. The role of radiosynovectomy will also be covered.

Orthopaedic problems and solutions

Dr Brett Halliday

(Abstract not available at time of printing)

SATURDAY 10 OCTOBER 2009

0900-1030

PLENARY 3 – THE IMPORTANCE OF COMPREHENSIVE CARE FOR PATIENTS, FAMILIES, HEALTH PROFESSIONALS AND THE HEALTH CARE SYSTEM – MEETING THE CHALLENGES

Room: Kennedy & Roosevelt

Chair: Kathy Mulder

Children's Hospital, Winnipeg, Canada

A young family's perspective of the comprehensive care model

Helen Fogarty

QLD

The Fogarty family lives in Brisbane with two sons with haemophilia (aged almost eight and almost two) and a four-year-old daughter. Their first son was diagnosed with severe haemophilia at six months of age when he began bruising inexplicably. With no family history of the condition, the family dealt with the diagnosis by learning as much as they could, accessing the full range of available help and by getting involved with the local haemophilia foundation. Two children later, including another with haemophilia, the family has benefited greatly from comprehensive care, including access to paediatric haematologists, specialist nurses, social workers, home treatment training, home visits, physiotherapy, occupational therapy, pharmacy, dental referrals, surgery, information resources, genetic counseling, obstetric advice and genetic testing. Most days, haemophilia is just part of their regular healthy lives, but when things do go wrong, the family has confidence in their Haemophilia Treatment Centre to help them get back on track.

A perspective of an adult with haemophilia

Mike O'Reilly

QLD

As a child with haemophilia in the 1950s, care was predominantly from parents and treatment from the medical profession reactive and limited by lack of knowledge and available technology at that time. As a result haemophiliacs suffered severe damage to weight bearing joints by their early teens.

In the mid 1960s a quantum leap occurred with the discovery of Factor VIII and IX and the availability of Cryoprecipitate to treat haemophilia. However any defined "treatment plan" appeared to come from the Blood Bank who provided product and information to doctors and principal hospitals in respective states. Each member of the haemophilia community had their own system of treatment depending upon which hospital and general practitioner looked after their needs. Still, the development of care could only be best described as "reactionary" as it was focused on providing factor and treatment post the trauma event. The tragic emergence of HIV and hep C viruses in

the blood supply in the 1980s drove the Haemophilia Foundation to pursue a more coordinated approach to treatment , both pre and post, from the health care community. The development of prophylaxis treatment for young haemophiliacs was a major advancement in the evolution of proactive care that will see positive results for the community into the future. HFA has been instrumental in developing a more comprehensive care program for all haemophiliacs, eg Haemophilia Centres at major hospitals in each state. As the haemophilia community ages we require a holistic approach to our total health requirements which encompasses not just classic haemophilia related treatment but specialist medical services covering general health issues. eg cardiovascular problems, diabetes etc. An holistic approach will improve quality of life, provide timely and appropriate medical services while reducing the demand long term on medical resources

Using evidence and experience – the benefits of benchmarking

Dr Chris Barnes

Royal Children’s Hospital, Melbourne, VIC

Haemophilia and other bleeding disorders are relatively uncommon yet complex medical disorders requiring subspecialist care in tertiary medical centers. With modern treatment, the quality of life of patients with bleeding disorders has been transformed but a number of medical and psychological issues continue to be sources of major morbidity in these patients. The delivery of care to these patients requires multidisciplinary teams to maximize the effect of medical treatment and to address the range of associated morbidities. The development of this comprehensive model of care for patients with bleeding disorders in Australia faces a number of unique state and national based challenges; many of which are based on the availability of suitably qualified and experienced personnel and varying access to resources. These challenges are particularly important in centers caring for smaller numbers of patients. As a result, the availability of comprehensive care of patients with haemophilia and other bleeding disorders varies. The role of benchmarking allows collection of information regarding the development of haemophilia care in different treatment centers, highlighting advantages of individual systems and provides the opportunity to support changes in systems that could be used to standardize comprehensive haemophilia care in Australia. The current presentation will provide information on the recent paediatric benchmarking initiative of haemophilia treatment centers in Australia.

History of comprehensive care and current best practice

Dr John Rowell

Haemophilia Centre, Royal Brisbane and Women's Hospital, QLD

'Haemophiliacs need special service' was the title of an article in 1956 noting the extra needs of persons with haemophilia. In 1949 Cohen et al described the 'Social adjustment of six patients with hemophilia prior to and during prophylactic treatment' – highlighting the awareness of social issues with haemophilia. During 50s and early 60s emphasis was on provision of effective plasma components or concentrates to treat haemorrhages. With the advent of home therapy, a further emphasis on regular supervision of a persons progress was required involving many specialists including nursing, physiotherapy, social work and other medical specialists and comprehensive care evolved. As issues within haemophilia and treatment options change – comprehensive care evolves with emphasis on home, education, prevention of complications through prophylaxis. There are now well established models and standards of comprehensive care that are implemented overseas and in Australia. These models need to be maintained and AHCDO is currently performing an audit of adult Haemophilia Centres as a benchmark.

Physiotherapy – an overview

Debbie Thompson

Children, Youth and Women's Health Service, Women's and Children's Hospital, SA

The Physiotherapist is an integral part of the team providing comprehensive care in haemophilia. The roles played within the haemophilia teams varies widely from state to state. The roles currently played by Physiotherapists working in haemophilia in Australia and New Zealand will be presented. This will be compared with results of a similar survey completed in 2005. The elements that constitute comprehensive care, challenges to delivering this and opportunities for the future will also be discussed.

Nurse – an overview

Janine Furnedge

Royal Children's Hospital, Melbourne, VIC

The role of the haemophilia nurse can vary greatly between Centres. Nurses usually play a key role in coordinating care and linking patients and their families with members of the comprehensive care team. This presentation will highlight the roles of haemophilia nurses across Australia.

Social Worker – an overview

Maureen Spilsbury

Queensland Haemophilia Centre, QLD

Over the years there have been a number of workers from a range of disciplines working as social workers, psychologists and counsellors within haemophilia communities across the Australian states and New Zealand. Each worker brings their own personality, experiences and skills to the role and this has led to the development of a range of creative programs and activities for adults and children in the community.

Despite the fact that the general community concept of social workers is most often negative, many have been in the positions for long periods of time and work alongside a team of other health workers and community members to meet the ideals of comprehensive care in haemophilia.

Workers agree that each work day is full of new experiences. At the end of many days the listed tasks are still unfinished as the urgency of haemophilia issues set the agenda of the day. The role is challenging and unusual within the hospital system, and the demands of the task do not fit neatly into the job description of a “ward” social worker. The haemophilia worker’s role is ideally about keeping people out of the hospital system and avoiding problems utilising the inherent strengths of each individual as opposed to providing short term support in acute situations. This presentation is an overview of the roles and tasks of haemophilia social workers and will also look at how current positions are structured within individual workplaces.

SATURDAY 10 OCTOBER 2009

1100-1230

CONCURRENT 1 – UNDERSTANDING GENETICS AND REPRODUCTIVE CHOICES

Room: Kennedy

Chair: Dr John Rowell

Haemophilia Centre, Royal Brisbane and Women's Hospital, QLD

An overview of genetics

Dr John Rowell

Haemophilia Centre, Royal Brisbane and Women's Hospital, QLD

Haemophilia is an X linked disorder producing clinical symptoms in males and occasionally females. Prior to the identification of the genes for haemophilia A (factor VIII) and haemophilia B (factor IX) in 1984 and 1982 respectively, coagulation testing was performed to identify possible carriers of the abnormal gene. This testing was not conclusive and when combined with an understanding of the family tree provided a probability of determining carrier status. Furthermore – if antenatal testing was being considered, obtaining samples was quite difficult and could make coagulation testing erroneous. In 1953 the genetic code using DNA was elucidated. This led to a greater understanding of how genes affected proteins and allowed identification of specific genes leading to better diagnosis and improved treatment products.

How genetic counselling can help

Katherine Rose

Genetic Health Services Victoria

Genetic counselling is a process that provides individuals and families with information, counselling, support, and assistance with decision making, surrounding the genetic condition in their family. Individuals with a family history of Haemophilia will often seek genetic counselling with many questions they would like answered, such as: What is the cause of Haemophilia?; Am I a carrier?; Is genetic testing relevant to me?; Who will be told my result?; What about children?; and, What about the rest of my family?

Genetic testing is available to determine the genetic fault (mutation) causing haemophilia in a family. Testing must be initiated in a male with haemophilia, or an obligate female carrier for haemophilia. Once the mutation is identified, accurate carrier testing is available to females in the family. The decision to have carrier testing is personal. Reproductive options for females who are carriers for Haemophilia are to either accept the risk, utilize reproductive technology (CVS or PGD), or adopt. I will present a case, which outlines some of the counselling issues that arise for families seeking genetic testing for Haemophilia.

PreImplantation genetic diagnosis and assisted reproductive technology in haemophilia

Dr Penelope Foster

Melbourne IVF and the Royal Women's Hospital, Melbourne, VIC

For couples at risk of transmitting haemophilia (where the male partner has haemophilia or the female partner is a known carrier), PGD offers the possibility of testing the embryo before implantation to determine its gender (gender selection), or its status (affected or unaffected) by gene detection. PGD may provide for some couples a more acceptable option than antenatal testing and a subsequent decision whether to terminate an affected pregnancy.

Couples where the male partner has HIV may be interested in the programme developed at the Chronic Viral Illness Clinic at the Royal Women's Hospital which offers fertility treatment to the female partners of HIV-infected men. The man needs to have undetectable viral load in blood and semen; screened semen is stored and used for in-vitro fertilization or intra-uterine insemination in the female partner.

A carrier's journey

Jane Devlin

VIC

In this personal account, Jane reaches her mid-thirties and starts to think about having a child, and therefore has to find a way of finally confronting the genetic implications of her family history. She has witnessed the long years of strain on her family as her mother devoted herself to caring for and protecting her brother who has haemophilia A. She has seen her brother suffer. It might be considered hard enough to find a suitable partner with whom to have a child, let alone a partner willing to embrace what these implications might mean.

After years of unconsciously - conveniently - suppressing her feelings and misgivings about her suspected carrier status, her biological clock finally sounds the alarm, and she finds herself in a meeting room with a clinical geneticist at Royal Melbourne Hospital. A journey is thus begun; through subsequent genetic counselling at The Alfred and gene testing, it is confirmed that she is a carrier. Not only are the medical facts and her reproductive choices established, but the genetic counselling she receives leaves her with a life-changing level of understanding, acceptance and peace. The birth of her daughter in December 2007 is the fulfillment of this journey.

SATURDAY 10 OCTOBER 2009

1100-1230

CONCURRENT 2 – HEPATITIS C

Room: Roosevelt

Chair: Suzanne O'Callaghan

Haemophilia Foundation Australia

Personal reflections on living with hepatitis C

Mark Ivory

QLD

Before making a commitment to undergo treatment I looked at the information available about treatment, and discovered that one type of hep C seemed to respond better to the current treatment regime than others. With my leave from work arranged I saw the nurse at the treatment centre in Cairns prior to commencing treatment. I learnt that I could not have unprotected sex while I was having this treatment, and definitely no alcohol during treatment either. Treatment began at the start of the year, and if successful would last six months. My blood test results were very positive and I had completed all of my treatment. It is worthwhile to get this treatment. Good luck to anyone undergoing treatment for hep C, or about to begin treatment.

Update on hepatitis C treatment and care and future directions

Dr Greg Dore

National Centre in HIV Epidemiology and Clinical Research, University of New South Wales

Treatment of chronic hepatitis C virus (HCV) infection has improved in recent years, particularly since the advent of pegylated interferon (PEG-IFN) and ribavirin (RBV) combination therapy, with 50%-80% (depending on HCV genotype) of people now achieving a sustained virological response following 24-48 weeks therapy. However, treatment rates remain low, in part related to considerable treatment-related toxicity and relatively prolonged therapy.

Two broad areas of chronic HCV therapy development are greater use of early virological monitoring to individualise treatment and the development of new therapeutic classes such as protease and polymerase inhibitors. The assessment of HCV viral load at week 12 of therapy (early virological response, EVR) has been the major virological timepoint for on-treatment decision-making (e.g. cessation if less than two log reduction from baseline HCV viral load). However, earlier HCV RNA measurement to provide information on rapid virological response (RVR, undetectable HCV RNA at week 4) has improved treatment individualisation. For example, patients with HCV genotype 1 with a low baseline HCV viral load who achieve an RVR may reduce therapy duration from 48 to 24 weeks.

The development of HCV protease and polymerase inhibitors should greatly enhance clinical management of chronic HCV infection. Phase I and II studies with these agents have revealed several important features. First, at least initially, these individual agents will be combined with PEG-IFN and RBV, although a phase I study is underway to examine a dual combination regimen of a protease and polymerase inhibitor. Second, triple therapy is likely to provide additional toxicity. Third, early HCV resistance is an important issue, particularly for protease inhibitors. Fourth, treatment responses should be improved by at least 15-20%, with shortened treatment durations.

These potential advances in chronic HCV therapy provide great optimism for people with HCV and their clinicians, and should enhance treatment uptake rates and reduced advanced liver disease burden.

Decisions about hepatitis C treatment and resilience during treatment

A/Prof Carla Treloar

University of New South Wales

This presentation will cover two projects. The first was a survey of people living with hepatitis C regarding their decisions about treatment. 111 people with bleeding disorders completed the survey. This presentation will cover the breakdown of treatment uptake, outcomes and intentions regarding future treatment. The second project is a qualitative study of people undergoing hepatitis C treatment. An important finding of this study was the resilience displayed in coping with treatment by participants with histories of other significant life challenges. Together, these studies provide important information about the uptake of hepatitis C treatment and strategies used by those undergoing treatment to cope with treatment.

Dealing with your mental health – managing hepatitis C symptoms and treatment

Dr Paul Pun, MBBS, FRANZCP

Consultation-Liaison team, Princess Alexandra Hospital, Brisbane, QLD

Interferon and ribavirin therapy have revolutionized the management of chronic hepatitis C infection, providing substantial cure rates for a large number of afflicted individuals. Neuropsychiatric side-effects of this treatment are being increasingly recognized as a significant phenomenon, affecting up to 30% of patients undergoing this therapy. Liaison psychiatrists are becoming increasingly involved with hepatology units in screening prior to treatment, and managing these side-effects of depression and anxiety. The presentation will describe the Queensland experience of screening and treatment for neuropsychiatric sequelae of interferon therapy, as well as reviewing the current evidence base informing such interventions.

SATURDAY 10 OCTOBER 2009

1100-1230

CONCURRENT 3 – FREE PAPERS

Room: Lincoln

Chair: Beryl Zeissink

Queensland Haemophilia Centre, Royal Brisbane & Women's Hospital

The HFNZ community needs assessment, preliminary findings

Chantal Lauzon

Haemophilia Foundation of New Zealand

In 2008, the Haemophilia Foundation of New Zealand (HFNZ) began a process to assess the needs of their membership in order to ensure that the bleeding disorder community in the New Zealand is adequately served. Due to advances in care, the needs of the membership can be expected to have changed in recent decades and HFNZ want to ensure that relevant and cost effective benefits are offered.

The needs assessment process consisted of two focus groups with members in January/February 2009, and a membership survey in June/July 2009. The focus group discussions were used to drive the development of the membership questionnaire on the various programmes and services offered by HFNZ. The questionnaire was distributed to the extended haemophilia community. Preliminary findings of the needs assessment will be presented.

A community review in late 2009 will then examine the preliminary findings before generating a final report. The key learnings of the needs assessment will be important tools for HFNZ as they outline a strategic plan to serve the New Zealand bleeding disorder community in the best way possible.

A retrospective audit of yttrium synovectomies done at the Ronald Sawers Haemophilia Centre at the Alfred Hospital, Melbourne

Dr Anne Powell

The Alfred Hospital, Melbourne, VIC

Yttrium synovectomies have been used in the mainstream treatment of secondary synovitis in haemophilia. In countries without access to prophylactic product, it is often used early to prevent ongoing joint bleeds. In our centre however, it is often used in patients with severe disease who have failed the conservative treatment of prophylaxis and intra-articular steroids. In 2008, 9 patients received a yttrium synovectomy at the Ronald Sawers Haemophilia Centre. This involved multiple joints including ankles, knees and elbows. Each patient had between one and three joints injected. Improvement was reported in only 3 patients and one reported an incomplete improvement. Side effects were common, with two cases of leakage, fortunately with no chronic sequelae. There was also one case of septic arthritis in a different joint to that injected. There was one possible bleed 2 days following the procedure.

Although our numbers are small, there appears to be a trend towards reduced efficacy and possibly increased morbidity from yttrium synovectomies compared to data published in 1994 from our centre. This is possibly due to increased baseline severity of patients as now they have often failed treatment with prophylaxis and intra-articular cortisone. Certainly the use of yttrium synovectomies in other forms of inflammatory arthritis is rarely indicated due to lack of efficacy documented in patients without haemophilia. This raises the issue as to when yttrium synovectomies should be indicated and a prospective trial on this question is now needed.

The psoas muscle and sexual health

Mathew Stewart

Queensland Haemophilia Centre, Royal Brisbane and Women's Hospital, QLD

Psoas muscle bleeds can be very painful and debilitating and can have significant consequences for an individual. Historically, there is some mystery surrounding the causes of bleeds into this muscle - often being labeled as spontaneous bleeds. This presentation seeks to briefly outline the psoas muscle's anatomy and biomechanics as well as overview some causes and consequences, assessment and management of bleeds into this muscle.

The involvement of the musculoskeletal system on one's sexual health appears to be largely overlooked in the framework of comprehensive care. Sexual health has a large bearing on an individual's quality of life for numerous reasons. The information presented about the psoas muscle will provide a background to an engaging discussion of its involvement in the sexual health of people with haemophilia. This will be used to demonstrate the importance of incorporating this topic in the comprehensive care of people with haemophilia.

Thirty years' experience of joint replacements in patients with bleeding disorders in South Australia

Dr Lay Tay

SA Pathology, IMVS and Adult Haemophilia Treatment Centre, Royal Adelaide Hospital, SA

Recurrent haemarthrosis is common in patients with severe and moderately severe bleeding disorders and this often affects weight-bearing joints such as knee and hip, and this progresses to chronic arthropathy which causes a reduced range of joint movement and chronic pain syndrome especially in the older patients who were not on primary prophylaxis in the past. Mild or moderate arthropathy is usually managed medically, but surgery is an option for those with severe functional impairment or pain.

Our centre has 139 adult patients with haemophilia A, of which 64 severe or moderately severe; 75 mild, and 31 patients with haemophilia B. Forty-four joint replacements/revisions (22 hip, 21 knee, 1 shoulder) were done. Forty-one surgeries were in haemophilia A, 1 in mild haemophilia B and 2 in VWD. Median age was 55 +/- 12.2 (Range 35-83). Seventy-two percent (32/44) were severe haemophilia A patients.

Prior to 1989, cryoprecipitate was used, then plasma-derived FVIII concentrates (AHF, Biostate) and recombinant FVIII (Recombinate and Advate and Refacto) depending on their availability; Monofix was used for Haemophilia B; Biostate for VWD. For FVIII replacement, AHF was used in twenty-three cases; Biostate in six (2 in VWD patients), Recombinate in three, Advate in six and Refacto in one.

Pharmacokinetic studies were routinely performed to plan treatment. Surgeries were covered by continuous factor infusion in the first 5 to 7 days, and subsequently bolus till day 31 in severe patients; patients with milder phenotype required much less treatment. Subgroup analysis of haemophilia A patients (n=34) showed median FVIII usage of 54,500 +/- 21,680U and (Range 12,000- 90,000U) with 3 cases (FVIII>100,000U) excluded because of extensive surgery or complicated recovery. Wound or joint infection was uncommon (3/44), and a haemophilia carrier developed DVT/PE.

Patient outcomes were generally excellent after joint replacements with improved QOL.

Outcomes after joint arthroplasty or arthrodesis at an Australian haemophilia centre

Dr Kemble Wang

The Alfred Hospital, Melbourne, VIC

Haemophilia can have a devastating effect on the joints, resulting in severe pain and disability and a reduced quality of life. In a cross-sectional review, we report on the outcomes of a cohort of haemophilia patients treated at a major Australian Haemophilia Centre who underwent joint arthroplasty or arthrodesis. Between 1985 and 2008, 56 patients had a joint procedure. 33 of these patients are still alive and were included in the study. The involved joints include 23 knee replacements, 13 hip replacements, 6 elbow replacements, and 13 ankle arthrodeses. Mean follow up is 9 years (range 1-24 years). 21 joints had at least one major complication, with the rate being higher in patients with co-existing HIV. Of the joints that had undergone knee replacements, mean Oxford Knee Score is 36.1 (33.1-39.1) and mean Knee Society Score (functional + clinical) is 135 (118-142). Of the joints that had undergone hip replacements, mean Oxford Hip Score is 37.6 (30.6-44.6) and mean Harris Hip Score is 69.5 (54.6-84.4). Mean Functional Independence Score in Haemophilia is 20.4

(19.1-21.6). 23 out of 30 patients report being very satisfied with improvement in pain from the operation. 16 out of 30 patients report being very satisfied with improvement in function from the operation. There is no correlation between length of time after joint surgery and satisfaction rates. Conclusion: despite high rates of complications and objective residual functional deficits, joint replacement and arthrodesis surgery translates into a high rate of patient satisfaction that persists over many years. In particular, the relief from pain is marked and long lasting.

Report on a survey of the use of portacaths

Dr Susan Russell

(Abstract not available at time of printing)

SATURDAY 10 OCTOBER 2009

1330-1500

CONCURRENT 1 – GOOD DENTAL CARE FOR ADULTS AND CHILDREN WITH BLEEDING DISORDERS

Room: Kennedy

Chair: Dr James Daly

Royal Hobart Hospital, TAS

Dental care and health in adults

Dr Ian Hewson

The Alfred Hospital, Melbourne, VIC

Haemophilia patients have in the past had a tendency to avoid dental treatment because of a fear of possible post treatment bleeding and dentists have had a reluctance to treat these patients due to the risk of bleeding. Good oral hygiene is essential for maintaining healthy gingival tissues and healthy gingival tissues do not bleed during conservative dental treatment. A recent study at The Alfred Hospital Melbourne using local haemostatic measures has indicated that oral surgery can be carried out with minimal factor support and a low risk of post operative bleeding.

The Great Australian Bite

Dr Kerrod Hallett

Royal Children's Hospital, Brisbane, QLD

This presentation describes the more common dental problems in children with bleeding disorders. Management of these problems requires a multidisciplinary team approach from the dental and haematology teams, generally in a tertiary level care paediatric hospital. However, many tooth and gum diseases can be successfully avoided with proper home care and preventive therapy by the dental team. Unexpected dental trauma can occur and can be very distressing for both the parent and child. Coordination with the local dentist and emergency management of bleeding from the mouth and the management of damaged teeth will be discussed. Specialist dental services such as orthodontic treatment (braces) and surgical care can be safely provided in the hospital environment. Most children can lead a relatively normal life and maintain a healthy dentition into their adult years without worries of early tooth loss or fear of dental procedures.

A personal experience

Paul Bonner

SA

Paul has severe haemophilia B and will share his dental experiences. He has a few fillings and at the age of 17 he had all four wisdom teeth removed. He currently has regular dental check ups.

SATURDAY 10 OCTOBER 2009

1330-1500

CONCURRENT 2 – LIVING WITH HIV

Room: Roosevelt

Chair: Alex Coombs

The Alfred Hospital, Melbourne, VIC

Psycho-social aspects of disclosure

Alex Coombs

The Alfred Hospital, Melbourne, VIC

Disclosure of a chronic illness such as HIV is an on-going concern for people with a bleeding disorder and can occur in many areas and arenas of a client's life. The theme of disclosure of one's HIV status in a social work context may require practical, legal and emotional support. Of specific specialty is the legal requirements, concepts such as shared responsibility for sex and risk and transmission issues. Disclosure may facilitate self acceptance of one's condition. It is a process that is life long and can have many psycho-social consequences on and for the individual. I will attempt to present some of the experiences of people with a bleeding disorder and living with HIV that I have encountered through several non-identifying case studies

Personal reflections

Matt Powell

VIC

Matt Powell is a 37 year old haemophiliac who contracted HIV virus as a child. In relation to HIV, Matt will discuss aspects of disclosure from two perspectives: how information has been disclosed to him by medical practitioners, and more particularly, how he has disclosed his status to family, friends, and others throughout his life with HIV.

Matt was informed about his HIV status in the mid-1980s, a time when AIDS was a mystery to the medical fraternity, and was (particularly through mass media coverage) creating panic in society at large. Matt will reflect upon the emotional and psychological impacts of this difficult early time. He will then talk to changing attitudes both in society and medicine through the 1990s and up until the present.

Although times have changed, the essential issues of disclosure remain. As HIV is an 'invisible' disease, it is up to the HIV positive person who to tell, when and why. These are complex choices that are as relevant now as they have ever been. Because HIV will strongly affect a person's sense of sexuality and self, whether to disclose or not to disclose will always be a difficult problem to act on. Matt hopes the discussion of his experience will give an insight that may have relevance for people dealing with these aspects of HIV/AIDS.

HIV in 2009 means viral suppression for all: new opportunities and new challenges

Dr Mark Kelly

AIDS Medical Unit, Community Programme, The Prince Charles Hospital, Brisbane, QLD

Most Australians with HIV can expect to achieve complete virological suppression in 2009 because of advances in HIV therapeutics. The capacity to achieve full virological suppression results in immune recovery and improvements in the life expectancy of patients with HIV. This optimism extends even to patients who developed resistance to first-line antiretroviral agents. New treatment options for such patients have been available in the past three years include: the CCR5 inhibitor maraviroc, the fusion inhibitor enfuvirtide, the integrase inhibitor raltegravir, the second generation non-nucleoside reverse transcriptase inhibitor etravirine and the second-generation protease inhibitors darunavir and tipranavir.

Traditional AIDS related illnesses are now rare. However cardiovascular, renal, hepatic and oncology mortality/morbidity is increased in patients with treated HIV. These illnesses are collectively referred to as serious non-AIDS events (SNAE). The capacity to achieve full virological suppression has permitted HIV discordant couples to achieve pregnancies safely and to look forward to rich lives as parents.

This paper will address new treatments for HIV; review the impact of serious non-AIDS events and outline strategies available for HIV discordant couples to plan to have a family.

Positively addressing personal barriers - lets talk about ... Sex, disclosure & relationships

Georgia Ash

Sexual Health & AIDS Counselling Service, QLD

For people living with haemophilia and HIV, life can be challenging. Many of the milestones that mark the traditional trajectory of their lives are complicated by medical conditions that often require frank and honest discussions with significant others. The issue of disclosing one's HIV status affects many areas including potential partners, forming relationships, negotiating safe sexual practices and considering options for having children. Without discussion and support, these issues can seriously impede a person's quality of life and can lead to psychological distress. This presentation will seek to address some of the personal barriers that people with HIV encounter by drawing on both anecdotal and evidence based research to assist people living with Haemophilia & HIV to live full and productive lives.

SATURDAY 10 OCTOBER 2009

1330-1500

CONCURRENT 3 – PRACTICAL LIVING

Room: Lincoln

Chair: Leonie Mudge

Royal Prince Alfred Hospital, Sydney, NSW

Employment and superannuation issues for people with bleeding disorders

John Berrill

Maurice Blackburn Pty Limited, VIC

A big part of practical living for people with bleeding disorders is their employment and financial security. Problems with work and financial difficulties can affect someone's self-esteem, cause stress and affect their health.

Superannuation and insurance rights and entitlements are an important component of this, particularly for people with chronic illnesses. Disability and death benefits are a feature of most employment superannuation funds and many people also have their own income protection, life insurance and travel insurance policies.

We will look at some of the insurance benefits you may be covered for, when and how to claim and your rights and entitlements.

Income support and other financial assistance

Leonie Mudge

Royal Prince Alfred Hospital, Sydney, NSW

This session will cover the Australian Government financial assistance program delivered by Centrelink. There will also be coverage of other programs of assistance administered by state governments, particularly those related to mobility issues. The focus will be on programs and benefits relevant to an adult with a bleeding disorder.

Career employment: challenges and choices - panel

Mike Holloway

QLD

I was born in the early fifties. My parents had been exposed to haemophilia through my mother who had three brothers and three or four cousins. She was one of six girls in her family but appeared to be the only one that was a carrier of the gene. I have two sisters who are carriers and a brother not affected, and I currently also have a nephew who has haemophilia.

My memories of growing up was of pain, swollen joints and spending long periods in bed being unable to move for the first week then slowly recovering over at least another week, and so it went on. Needless to say my attendance at school was limited, only completing two years of high school.

After becoming eligible for a pension, that then appeared to be my future, as employment in the country was limited for someone with my issues.

Moving to Sydney was a life changing experience, as regular treatments were available to me as well as support through the Social Workers and Training Programs that were available. Thanks to the encouragement from health professionals, family and friends I have been employed in a number of areas over the past 35 years.

Luke Chipperfield

NSW

Developing a career is challenging for everyone, but doing so with a chronic condition such as haemophilia requires more planning and determination.

Choosing a career in Civil Engineering seems easy looking back; however, it took a few months of exploring my career choice and experiencing the inevitable setbacks before realizing I had made the right decision.

Throughout my career I have developed strategies to strike a good work – life balance. Understanding my own strengths and limitations has been an important component of this.

This presentation will cover my work experiences and some of the challenges I have come up against integrating the needs of my health into my career.

Robert McCabe

WA

Choosing what to do for a living is a very difficult choice to make. However, it should not be made more difficult because of a medical condition. People who have a bleeding disorder or care for someone who does do have additional considerations when looking at long term career options. These considerations do not make it any easier for any person looking to embark on a career path.

I will share some of the things that I focused on when I decided on a career in the law. Some of these included

- 1 I focused on what I was interested in.
- 2 I was realistic in considering my options.
- 3 Set personal goals, both in the short and long term.
4. Know your rights. This will make you feel more in control of the path you chose.
5. Don't take it too seriously. You work to live, not live to work!

SATURDAY 10 OCTOBER 2009

1530-1650

**PLENARY 4 – HAEMOPHILIA CARE AND TREATMENT –
WHERE HAVE WE COME FROM AND WHERE ARE WE GOING?**

Room: Kennedy & Roosevelt

Chair: Deon York

Haemophilia Foundation of New Zealand

History of haemophilia care, new treatments, treatment needs in the developing world

Dr Paula Bolton-Maggs

Manchester Royal Infirmary, Manchester UK

Haemophilia has been described since ancient times. The sex linked inheritance was well known in the 1800s and is well demonstrated in the family of Queen Victoria. Plasma transfusion developed in the 1900s was effective but difficult due to the large volumes required. A major advance was the discovery of cryoprecipitate in 1965. This was followed in the 1970s by development of concentrates which permitted home therapy and a significant improvement in quality of life. The tragedy of HIV and HCV infections has had a profound effect on the haemophilia community, but the advent of recombinant products and the success of prophylaxis in preventing long term joint damage mean a bright future for children with haemophilia in developed countries. Research is focused on delivering factor products with longer half lives, gene therapy and improved methods of antenatal diagnosis. Products are needed for the rare disorders and a number are currently in clinical trials. The situation is different in many parts of the world where economics and other medical priorities make provision of haemophilia treatment difficult, but the World Federation of Haemophilia is working effectively with its national member organisations to change this with the intent of 'treatment for all', including for von Willebrand disease and the rare bleeding disorders. Several strategies are needed including support for safe transfusion services, training in advocacy as well as of medical and nursing personnel in the development and sustaining of comprehensive care.

Gene Therapy for Haemophilia: what's the holdup?

Prof John Rasko

Cell & Molecular Therapies, Royal Prince Alfred Hospital, NSW

Gene therapy promises compelling advantages for the treatment of diverse diseases with a genetic component, including many that affect the blood. These advantages include the production of protein(s) by endogenous cells, minimisation of exposure to exogenous pathogens, long-term correction of inherited disorders and novel therapeutic opportunities. We have completed a Phase I dose escalation study of liver-directed AAV2-FIX in humans with severe hemophilia B (Nature Medicine, 2006 Mar;12(3):342-7). The rationale for the clinical trial was based on studies in mice, hemophilic dogs, and

non-human primates demonstrating long-term (>4 yrs) expression of Factor IX (FIX) after infusion of an AAV vector expressing FIX into the portal vein or the hepatic artery. Seven human subjects were treated in total: two subjects treated at the highest dose showed detectable circulating levels of FIX (maximum 11.8% and 3% respectively). Transgene expression was transient and accompanied in two cases by a reversible asymptomatic elevation of liver enzymes. There was no evidence of a FIX inhibitor at any point. Assessment of the CD8+ T cell immune response to AAV-2 supported a model in which a briefly detectable response to AAV capsid epitopes resulted in elimination of the transduced cells (Nature Medicine, 2007;13(4):419-22 IF: 26.382). We concluded that AAV-2 vectors can transduce human hepatocytes in vivo, but that long-term expression was prevented by a specific immune response. In order to circumvent this limitation, we are now enrolling for a trial involving transient immune suppression – although other approaches including different pseudotyped AAV vectors are also under consideration. The rationale and risks and for the safety and dose escalation study will be discussed. The study will evaluate potential efficacy in each dose group. Pre-existing immunity to AAV and its relationship to gene expression (or transgene activity) will also be assessed, as will the potential for germline transmission of vector administered into the liver.

Further Reading

John E J Rasko, *Dare We Imagine A Cure For Haemophilia?* National Haemophilia, March 2009

Viiala, N.O., Larsen S.R. and Rasko J.E.J, *Gene Therapy for Hemophilia: Clinical Trials and Technical Tribulations, Seminars in Thrombosis & Hemostasis*, 2009;35(1):81-92

Trends in treatment product use and expenditure in Australia

Dr Alison Turner

National Blood Authority, ACT

The demographics of the Australian haemophilia community will be presented and the costs of clotting factor products shown. Information concerning the types of products used to treat haemophilia in Australia will be presented, including the trends in the number of product issues to the clinical community. By drawing on information collected over the last 6 years the presenter will identify changing product trends, including those between plasma derived and recombinant products. Data on the cost of products in Australia will also be presented. This is supplemented with international data on issuance of FVIII. Differences in clinical practice as illustrated by product demand at a jurisdictional level will be discussed. The Government's commitment to a secure supply of safe and affordable products to treat haemophilia will be outlined, along with factors which will help ensure efficient product management.

Ethics, cost and sustainability: the future horizon?

Deon York

Haemophilia Foundation of New Zealand

Typically, discussions around ethics in the bleeding disorders community centre on the application of genetic technologies for screening and diagnosis. As these technologies have been progressively introduced there has been space to debate their application and their contribution to a sustainable future. A sustainable treatment future also calls for some debate and consideration of the wider health context within which our community operates and the associated cost implications that bleeding disorders carry. As the last session of this conference, the goal of this overview is to provide some thought-provoking considerations of ethics, cost and sustainability. What does a sustainable future look like for the bleeding disorders community? What are our collective responsibilities in ensuring that future?



EVALUATION FORM

1. Overall

How would you rate the 15th Australian & New Zealand Haemophilia Conference overall?
 (Please circle one) Excellent Good Acceptable Sub standard

Comments: _____

2. Program

How would you rate the Conference program?
 (Please circle one) Excellent Good Acceptable Sub standard

Comments: _____

3. Speakers

How would you rate the speakers at the Conference?
 (Please circle one) Excellent Good Acceptable Sub standard

Comments: _____

4. Welcome & Exhibition Opening

How would you rate the Welcome & Exhibition opening?
 (Please circle one) Excellent Good Acceptable Sub standard

Comments: _____

5. Exhibition

How would you rate the Exhibition?
 (Please circle one) Excellent Good Acceptable Sub standard

Comments: _____

6. Program Sessions

How would you rate the sessions (please rate sessions you attended)?

| | Excellent | Good | Poor |
|--|-----------|------|------|
| <i>Friday 9 October</i> | | | |
| Plenary 1 – Assessing the impact of chronic disease on Adolescents – a practical psychological paradigm Comments: | | | |
| Concurrent 1– Family Factors: Challenges & Solutions Comments: | | | |
| Concurrent 2 – Product Safety Comments: | | | |
| Concurrent 3– von Willebrand Disorder Comments: | | | |
| Concurrent 1 – Women's Issues Comments: | | | |
| Concurrent 2 – Treatment & Management of Inhibitors Comments: | | | |
| Concurrent 3 – Haemophilia across the continuum Comments: | | | |
| Plenary 2 – Good joints for a better life Comments: | | | |

| | | | |
|--|--|--|--|
| <i>Saturday 10 October</i> | | | |
| Plenary 3 – Comprehensive Care | | | |
| Concurrent 1 – Understanding genetics and reproductive choices Comments: | | | |
| Concurrent 2 – Hepatitis C Comments: | | | |
| Concurrent 3 – Free Papers Comments: | | | |
| Concurrent 1 –Dental Care Comments: | | | |
| Concurrent 2 – Living with HIV Comments: | | | |
| Concurrent 3 – Practical Living Comments: | | | |
| Plenary 4 – Haemophilia care and treatment – where have we come from, and where are we going? Comments: | | | |

7. What additional topics would have improved the Program?

(Please list your suggestions) _____

8. Hotel and meeting rooms

How would you rate the Sebel hotel and meeting rooms?

(Please circle one) Excellent Good Acceptable Sub standard

Comments: _____

9. Gala Dinner

How would you rate the Gala Dinner?

(Please circle one) Excellent Good Acceptable Sub standard

Comments: _____

10. Conference organisation

How would you rate the Conference organisation?

(Please circle one) Excellent Good Acceptable Sub standard

Comments: _____

11. What further information would have been useful in your preparation for the conference or when you arrived?

(Please list your suggestions) _____

12. Your suggestions for the future

Do you have any suggestions for future conferences?

Comments: _____

Please hand form to the Haemophilia Foundation Australia Booth or the Registration and Information Desk or to HFA Conference Staff, or return it to either address or fax below -

Haemophilia Foundation Australia, 1624 High Street, Glen Iris, Vic 3146 F:03 9885 1800

MANY THANKS FOR TAKING THE TIME TO COMPLETE THIS SURVEY!



MAJOR CONFERENCE PATRON

Baxter

SPECIAL CONFERENCE PARTNERS
CSL Bioplasma, Novo Nordisk, Wyeth

CONFERENCE PARTNER
Octapharma Australia