14th Australian & New Zealand Haemophilia Conference
Canberra 4-7 October 2007

bleeding disorders ~ achieving success to last a lifetime

www.haemophilia.org.au

Conference Handbook and Abstracts
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Welcome to the 14th Australian & New Zealand Haemophilia Conference in Canberra hosted by Haemophilia Foundation Australia.

As the bleeding disorders communities of Australia and New Zealand come together for the 2007 conference and its related workshops I know you will enjoy the opportunities for discussion and learning. I trust you will return home with valuable new information, updated skills and a renewed enthusiasm to make a difference!

Sir Ninian Stephen
National Patron
Haemophilia Foundation Australia
WELCOME

We welcome you to the 14th Australian & New Zealand Haemophilia Conference in Canberra.

People with bleeding disorders and their families, health professionals, decision makers and industry representatives will have an opportunity to share their knowledge in discussions about current and future issues for clinical practice and policy affecting the treatment, care and education needs of people with bleeding disorders.

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

The interesting and diverse program is supported by a social program which will also be a great opportunity for stakeholders to come together, share ideas, make plans for the future and have fun!

We hope you enjoy the 14th Australian & New Zealand Haemophilia 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 Scott Dunkley
Chair
Conference Program Committee

Program Committee

Dr Scott Dunkley (Chair)  Royal Prince Alfred Hospital, Sydney
Kelly Brady  Royal Children’s Hospital, Brisbane
Belinda Burnett  Haemophilia Foundation of New Zealand
Sharon Caris  Haemophilia Foundation Australia
Anne Jackson  Women’s & Children’s Hospital, Adelaide
Peter Mathews  Haemophilia Foundation New South Wales
Vicky Mrowinski  Australian Haemophilia Centre Directors’ Organisation
Dr Michael Pidcock  The Canberra Hospital
Clare Reeves  Haemophilia Foundation Australian Capital Territory
Fiona Rennison (until March 2007)  Royal Prince Alfred Hospital, Sydney
Dr Susan Russell  Sydney Children’s Hospital
Gwen Sampson  The Canberra Hospital
Dr Mark Smith  Christchurch Hospital
Deon York  Haemophilia Foundation of New Zealand
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
Hyatt Canberra
Commonwealth Avenue, Yarralumla ACT 2600
P: 02 6270 1234

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 at the Hyatt is available to all guests.

Registration and Information Desk
All enquiries should be directed to the Registration and Information Desk in the Galley (see venue map on page 6), which will be open at the times listed below. Please check noticeboard near the Registration and Information Desk for daily updates and changes to session times.

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

**Haemophilia Treatment**
There is no treatment room at the Conference venue. The haemophilia centre in Canberra is located at:

The Canberra Hospital
Haemophilia Centre
Yamba Drive, Garran ACT 2605
P: 02 6244 2222

**Childcare**
Childcare is not available. Children are not permitted in Conference sessions.
SOCIAL PROGRAM

WELCOME COCKTAIL PARTY
Thursday 4 October at 1830-1930, Atrium, Hyatt

Come along to our Welcome Cocktail Party 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 5 October at 1800-1830
Nara Park, Canberra

The Remembrance Service is a time for Conference delegates 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.

Nara Park is located behind the Hyatt, approximately a 5 min walk. Please advise staff at the Registration & Information desk if assistance is required to attend.

GALA DINNER
Friday 5 October at 1930 till late

The Gala Dinner will be held at the Hyatt 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 by Thursday 4 October at 1830. Please see Registration and Information Desk for more information.

The Gala Dinner is a free seating event.
EXHIBITION DIRECTORY

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

CSL Limited Bioplasma Division
Contact: Michael Grant
189-209 Camp Rd, Broadmeadows, VIC 3047
P: 1800 063 892

Wyeth Australia Pty Ltd
Contact: Phillip Chain
Locked Bag 5002, Baulkham Hills, NSW 2153
P: 1800 555 057

Novo Nordisk Pharmaceuticals Pty Ltd
Contact: Nnamdi Udechuku
Level 3, 21 Solent Circuit, Baulkham Hills, NSW 2153
P: 1800 668 626

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

Hepatitis Australia
Contact: Helen Tyrrell
PO Box 716, Woden, ACT 2606
P: 02 6232 4257

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

Haemophilia Foundation of New Zealand
Contact: Belinda Burnett
PO Box 16582, Hornby, Christchurch, NEW ZEALAND
P: +64 3 344 5204
### 14th Australian & New Zealand Haemophilia Conference
#### Official Program

**THURSDAY 4 OCTOBER 2007**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>1830-1930</td>
<td>Welcome Cocktail Party</td>
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<td>Hyatt Canberra</td>
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**FRIDAY 5 OCTOBER 2007**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>0845-0900</td>
<td>Official Welcome</td>
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<tr>
<td></td>
<td>Gavin Fitzgerald (President HFA) and Deon York (President HFNZ)</td>
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<tr>
<td>0900-1030</td>
<td>Plenary 1</td>
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<tr>
<td></td>
<td>Key issues in haemophilia 1</td>
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<td></td>
<td>Room: Federation Ballroom</td>
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<td></td>
<td>Chair: Dr Scott Dunkley</td>
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<tr>
<td></td>
<td>“Ethnomics”, identity and agency in haemophilia care</td>
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<td></td>
<td>A/Prof lan Kerridge</td>
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<td></td>
<td>The role of health-related quality of life for outcome assessment in</td>
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<td></td>
<td>haemophilia</td>
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<td></td>
<td>Dr Kathelen Fischer</td>
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<tr>
<td>1030-1100</td>
<td>Morning Tea</td>
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<td>1100-1230</td>
<td>Concurrent 1</td>
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<tr>
<td></td>
<td>Inhibitor risk profiling – the care and management of inhibitors</td>
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<td>Room: Federation North</td>
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<td>Chair: A/Prof John Lloyd</td>
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<td>Living with an inhibitor - a personal reflection</td>
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<td>Michael Prendergast</td>
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<td>Predicting inhibitors</td>
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<td>Dr Jamie Price</td>
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<td>Role of plasma products in the treatment of haemophilia today</td>
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<td></td>
<td>Dr Scott Dunkley</td>
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<td>Treatment of patients with inhibitors and immune tolerance</td>
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<td></td>
<td>Dr Chris Barnes</td>
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<tr>
<td>1230-1330</td>
<td>Lunch</td>
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<td>1330-1500</td>
<td>Concurrent 1</td>
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<tr>
<td></td>
<td>Understanding von Willebrand Disorder</td>
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<td>Room: Federation North</td>
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<td>Chair: Dr Ross Baker</td>
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<td></td>
<td>Some practical aspects of laboratory testing for von Willebrand Disorder</td>
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<td>Dr Geoff Karshaw</td>
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<td>Demystifying the classification of von Willebrand Disorder and lessons from the Australian clinical trials</td>
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<td></td>
<td>Dr Ross Baker</td>
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<td></td>
<td>1 + 1 = 3 - A family experience of von Willebrand Disorder</td>
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<td></td>
<td>Lorraine Bishop</td>
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<tr>
<td>1500-1530</td>
<td>Afternoon Tea</td>
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<tr>
<td>1530-1700</td>
<td>Plenary 2</td>
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<tr>
<td></td>
<td>You won’t die from laughing</td>
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<td></td>
<td>Room: Federation Ballroom</td>
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<td>Facilitators: Patricia Cameron-Hill and Shayne Yates</td>
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<tr>
<td>1800-1830</td>
<td>Remembrance Service</td>
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<td></td>
<td>Nara Park, Canberra</td>
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<tr>
<td>1930-Late</td>
<td>Gala Dinner at Hyatt</td>
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<td>Room: Federation Ballroom</td>
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<td>Tickets are $55 and must be pre-purchased</td>
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**Concurrent 2**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td></td>
<td>Helping families to manage bleeding disorders better</td>
</tr>
<tr>
<td></td>
<td>Room: Federation South</td>
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<td>Chair: Clare Reeves &amp; Kelly Brady</td>
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**Concurrent 3**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tr>
<td></td>
<td>Hepatitis C treatment and care</td>
</tr>
<tr>
<td></td>
<td>Room: Canberra Room</td>
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<td>Chair: Dr Michael Picock</td>
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**Positively negative**

- Neil Boal

**Hepatitis C treatment and care: relevance to haemophilia**

- Prof Geoffrey Farrell

**Making decisions about hepatitis C treatment: what men are thinking**

- Dr Stephen McNally

**Panel discussion**

- Anne Jackson & Sharyn Whitaker

**Concurrent 2**

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<thead>
<tr>
<th>Time</th>
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<tbody>
<tr>
<td></td>
<td>Youth matters</td>
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<tr>
<td></td>
<td>Room: Federation South</td>
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<td>Chair: Maureen Spilsbury &amp; Robert McCabe</td>
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**Concurrent 3**

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<thead>
<tr>
<th>Time</th>
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<tr>
<td></td>
<td>Fitness in children</td>
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<td></td>
<td>Room: Canberra Room</td>
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<td>Chair: Gwen Sampson</td>
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**Fitness and physical activity in children with haemophilia**

- Dr Carolyn Brodnerick

**Strategies to promote healthy participation – overcoming the barriers**

- Wendy Poulton and Selena Griffin

**Auckland Islands sea kayak adventure**

- "Bloody Can Do It" - Jack Finn
### SATURDAY 6 OCTOBER 2007

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<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Chair</th>
<th>Room</th>
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<tbody>
<tr>
<td>0900-1030</td>
<td>Plenary 3&lt;br&gt;Key issues in haemophilia 1&lt;br&gt;Room: Federation Ballroom</td>
<td>Dr John Rowell</td>
<td>Federation Ballroom</td>
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<td></td>
<td>Individualisation of prophylactic treatment of severe haemophilia: when to start and when to stop</td>
<td>Dr Kathryn Fischer</td>
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<td>Pre-implantation genetic diagnosis and assisted reproductive technology in haemophilia</td>
<td>Dr Penelope Foster</td>
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<td>Panel discussion</td>
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<td>1030-1100</td>
<td>Morning Tea</td>
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<tr>
<td>1100-1230</td>
<td>Concurrent 1&lt;br&gt;Complications of ageing&lt;br&gt;Room: Federation North</td>
<td>A/Prof Alison Street</td>
<td>Federation North</td>
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<td>Vascular disease in haemophilia&lt;br&gt;A/Prof Alison Street</td>
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<td>Chronic haemophilic arthropathy&lt;br&gt;Prof John York</td>
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<td></td>
<td>Falls and balance – from research to practice&lt;br&gt;Marcia Feam &amp; Prof Keith Hill</td>
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<td>Concurrent 2&lt;br&gt;Impact of hepatitis C&lt;br&gt;Room: Federation South</td>
<td>Steve Waring</td>
<td>Federation South</td>
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<td>Hepatitis C and young people&lt;br&gt;Vicki Jermyan</td>
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<td>Hepatitis C related stigma and discrimination - origins, impacts and responses&lt;br&gt;Helen Tyrrell</td>
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<td></td>
<td>Experiences of the bleeding disorders community – HFA needs assessment&lt;br&gt;Suzanne O’Callaghan</td>
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<td></td>
<td>Concurrent 3&lt;br&gt;Women’s wisdom&lt;br&gt;Room: Canberra Room</td>
<td>Belinda Burnett</td>
<td>Canberra Room</td>
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<td>Mothers, partners, carers, people with bleeding disorders and carriers of the haemophilia gene</td>
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<td>Belinda Burnett</td>
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<td>Using genetic counselling services&lt;br&gt;TBC</td>
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<td>Menorrhagia: best care and practice&lt;br&gt;Dr Julia Phillips</td>
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<td>Management of delivery in carriers &amp; management of the newborn&lt;br&gt;Dr Susan Russell</td>
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<td>Panel discussion</td>
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<td>1230-1330</td>
<td>Lunch</td>
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<tr>
<td>1330-1500</td>
<td>Concurrent 1&lt;br&gt;Scientific and psychosocial snapshots – new initiatives and progress&lt;br&gt;Room: Federation North</td>
<td>Dr Scott Dunkley</td>
<td>Federation North</td>
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<td>The measurement of physical activity in boys with severe haemophilia&lt;br&gt;Brendan Egan</td>
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<td>Workshop for young women and bleeding disorders&lt;br&gt;Colleen McKay</td>
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<td>Attitudes towards and beliefs about genetic testing in the haemophilia community&lt;br&gt;Denise Herbert</td>
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<td>A retrospective study of the utility of the 1-deamino-8-D-arginine vasopresin (DDAVP) trial in the management of patients with von Willebrand disorder&lt;br&gt;Dr Jake Shott</td>
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<td>Blood, toluidine and tears: clinical and psychosocial outcomes over 25 years in patients with haemophilia infected with HIV&lt;br&gt;Dr Mark Polizzotto</td>
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<td>The safety and efficacy of enfuvirtide therapy for HIV infection in patients with haemophilia&lt;br&gt;Dr Mark Polizzotto</td>
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<td></td>
<td>Concurrent 2&lt;br&gt;Men’s health - it’s blokes’ business&lt;br&gt;Room: Federation South</td>
<td>Peter Mathews</td>
<td>Federation South</td>
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<td>Managing arthritis&lt;br&gt;Arthritis ACT</td>
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<td>Dealing with depression&lt;br&gt;Dr Paul Pentorough</td>
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<td>Panel discussion</td>
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<td>Concurrent 3&lt;br&gt;Planning and managing best practice care and treatment&lt;br&gt;Room: Canberra Room</td>
<td>Dr John Rowell</td>
<td>Canberra Room</td>
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<td>Using data for better clinical outcomes&lt;br&gt;Dr Ross Baker</td>
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<td>The NBA four years on - focus on patient needs, achievements and future opportunities&lt;br&gt;Dr Alison Turner</td>
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<td>Blood products for the treatment of haemophilia: priorities for government&lt;br&gt;Roderick Saunders</td>
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<td>Safety of haemophilia products - keeping ahead through regulation&lt;br&gt;Prof Albert Favugia</td>
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<tr>
<td>1500-1530</td>
<td>Afternoon tea</td>
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<tr>
<td>1530-1550</td>
<td>Plenary 4&lt;br&gt;Conference Closing... and what about the future?&lt;br&gt;Room: Federation Ballroom</td>
<td>Dr Scott Dunkley</td>
<td>Federation Ballroom</td>
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<td>Panel – Dr Chris Barnes, Dr Kathryn Fischer, Prof Albert Favugia, Deon York</td>
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<td>1550-1700</td>
<td>Closing remarks&lt;br&gt;Rob Christie (VP Finance World Federation of Hemophilia), Gavin Finkelstein (President HFA) &amp; Deon York (President HFNZ)</td>
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### SUNDAY 7 OCTOBER 2007

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<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Details</th>
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<tbody>
<tr>
<td>0830-1000</td>
<td><strong>Men’s Breakfast</strong>&lt;br&gt;Speakers: Brendan Egan and Jack Finn&lt;br&gt;Room: Federation Ballroom</td>
<td>Tickets are $65 and must be pre-purchased. Brendan is a physiotherapist at the Royal Children's Hospital, Melbourne. Jack is a person with haemophilia and an adventurer from New Zealand.</td>
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<tr>
<td>1015-1130</td>
<td><strong>Building stronger haemophilia organisations</strong>&lt;br&gt;Facilitators: Sharon Cans and Belinda Burnett&lt;br&gt;Room: Assembly Boardroom</td>
<td>Workshop for staff and volunteers of haemophilia foundations and will include a range of speakers on key issues for haemophilia organisations.</td>
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<tr>
<td>1145-1400</td>
<td><strong>Youth Program – Golf and lunch (Optional)</strong></td>
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<tr>
<td>1400-1500</td>
<td><strong>Youth Program – Daytime</strong>&lt;br&gt;Facilitators: Paul Bonnier &amp; Robert McCabe&lt;br&gt;Room: TBC</td>
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‘Ethnomics’, identity and agency in haemophilia care  
~ A/Prof Ian Kerridge, University of Sydney, NSW

Technological advances have substantially changed the lives of many people with haemophilia, at least in the industrialised world, as the majority of the international haemophilia community continue to lack access to adequate care. Australian patients can expect high standards of blood safety, coordinated models of haemophilia care, more intense therapy for the management and prevention of bleeds, prophylactic factor replacement in childhood, aggressive treatment of factor inhibitors and appropriate referral for orthopaedic and reproductive care. And despite slow progress, there remains the possibility of gene therapy.

While improvements in care, life expectancy and quality of life have created new possibilities, they have also created new, and complex questions regarding the appropriate goals, limits and organisation of haemophilia services. These questions are not unique to the haemophilia community, as no person or group has an unlimited claim on health resources. But whereas we, as a society, have generally avoided confronting issues of opportunity cost, the rapid rise in the costs of factor replacement and the chronic needs of people with haemophilia will demand that such questions are confronted sooner, rather than later. These questions are important, not only because they are primarily moral questions, but because they raise philosophical issues relating to identity, agency, disease and disability, and political issues relating to the organisation of haemophilia care and the development of clinical practice guidelines.

The role of health-related quality of life for outcome assessment in haemophilia  
~ Dr Kathelijn Fischer, Department of Haematology, UMCU, Utrecht

Choosing outcome parameters to assess results of haemophilia treatment requires the choice of a perspective: the patient’s perspective, the third party payer’s perspective, or the societal perspective.

From the patient’s perspective, avoiding bleeds and preserving joint function and health-related quality of life (HRQoL) are the most important outcome parameters. From the third party payer’s perspective, the main benefits of
intensive treatment are the additional medical costs avoided. From the societal perspective, benefits of treatment are the improved labourforce participation and Quality Adjusted Life Years (QALY’s). QALY’s are derived by attaching a value (utility) to HRQoL: with values ranging from 0 (death) to 1 (perfect health).

Over the last few years, assessment of HRQoL as outcome in the evaluation of treatment results has increased sharply. The generic Short Form 36 (SF 36) questionnaire and the Euroqol questionnaire for measuring preference based HRQoL have been used most frequently. Recently, two disease-specific questionnaires have been developed for children with haemophilia (Hemoqol and CHOKLAT). For adults, a haemophilia-specific instrument has been developed only in 2005.

Until now, six studies, including 56 to 903 patients, have described the effects of haemophilia treatment on HRQoL measured by the SF 36. These studies suggest that treatment is associated with the physical domains of health described by the SF 36, especially the domain of ‘physical function’. All show that HRQoL in haemophilia patients is decreased compared to the general population. In addition, HIV infection, frequent joint bleeds, and increasing age reduce HRQoL.

Several studies have shown that both age and arthropathy independently reduce HRQoL, and preliminary results from our own work suggest that the association of the SF36-domain of ‘physical function’ and Utility measured by the EQ5D with joint damage is considerable.

These findings support that measuring HRQoL is important for patients, doctors, as well as policy makers, and should be included in any thorough patient assessment.
FRIDAY 5 OCTOBER 2007
1100-1230
CONCURRENT 1 - INHIBITOR RISK PROFILING
– THE CARE AND MANAGEMENT OF INHIBITORS
Room: Federation Ballroom North
Chair: A/Prof John Lloyd, Royal Adelaide Hospital, SA

Living with an Inhibitor – a personal reflection
~ Michael Prendergast, Haemophilia Foundation Victoria

Michael is a 25 year old man living with severe haemophilia A with inhibitors and von Willebrand Disorder. Michael will discuss his challenges faced, not only with haemophilia, but the added dimension that inhibitors have brought to his life. He will however show that living with complications of haemophilia need not dampen his direction in life, as he continues to work full time as a town planner, travel the world and enjoy his favourite pastime of four wheel driving.

Predicting inhibitors
~ Dr Jamie Price, Princess Margaret Hospital, WA

Development of inhibitor antibodies is now one of the most serious complications of the treatment of haemophilia. Inhibitors occur in up to 30% of patients with haemophilia A and a much smaller proportion of patients with haemophilia B. Factors which influence the development of inhibitors include genetic and non-inherited risk factors. Established genetic factors include high risk factor VIII genotype such as large deletions, a family history of inhibitors and certain ethnic groups. Other risk factors are less well established but include age at first treatment, treatment intensity and type and environmental factors such as concomitant infection and vaccination. Development of inhibitors occurs early in the treatment of patients, usually in the first 10-20 exposure days and early detection of an inhibitor is a key to a better outcome with tolerisation therapy.

Role of plasma products in the treatment of haemophilia today
~ Dr Scott Dunkley, Royal Prince Alfred Hospital, NSW

Australia has the most advanced and safest products available for haemophilia care. Recombinant products are available to all and can eliminate the risk of blood borne pathogens. Likewise, due to advancements in manufacturing technique modern plasma products carry negligible risk of disease transmission. The majority of PTP’s and all PUP’s in Australia now use recombinant products an approach endorsed by AHCDO, yet in certain circumstances plasma products may represent a suitable alternative.
The greatest problem facing haemophilia care today is the development of inhibitors. Recently several international publications have raised the concern that there may be a higher inhibitor rate with recombinant products as compared to plasma products. The evidence however is far from complete and the issue highly controversial. However to highlight this issue, some European centres offer treatment with plasma concentrates to PUP’s they deem at high risk of inhibitor development.

Somewhat less emotive, and yet equally controversial, is the use of recombinant versus plasma product for immune tolerisation therapy in patients who have developed an inhibitor. In high risk patients plasma products may offer unique pathophysiological advantages. The AHCDO policy regarding recommended product choice for inhibitor treatment is currently under review. These issues will be discussed and explored during this session.

Treatment of patients with inhibitors and immune tolerance
~ Dr Chris Barnes, Royal Children's Hospital, VIC

The development of an inhibitor (allo-antibody) to infused factor VIII (FVIII) or factor IX (FIX) is the most serious complication currently affecting the management of patients with haemophilia. Estimates of the cumulative incidence of inhibitors to FVIII vary but may be as high as 52% in patients with severe haemophilia A. Inhibitors render prophylaxis and treatment of bleeds with clotting factor concentrate ineffective and there are limited treatment options available for patients who develop high titre inhibitors to FVIII or FIX.

Eradication of inhibitors with immune tolerance therapy to permit resumption of prophylaxis and treatment with clotting factor concentrates is the most desirable approach for these patients. Immune tolerance therapy relies on repetitive high dose antigen with or without immune modulation and attempts to overwhelm the immune response leading to immune tolerance to the foreign FVIII/ FIX antigen. A variety of immune tolerance therapy protocols have been developed that differ in regard to the dose and schedule of clotting factor infusions, and in the use of concomitant immune modulating therapies.

This presentation will focus a review of the current literature regarding options for treatment for patients with high titre inhibitors to FVIII and FIX including current recommendation for the institution and continuation and completion of immune tolerance therapy.
Understanding pain and needle phobia - comfort and coping strategies
~ Dr Angela Mackenzie, Royal Children’s Hospital, VIC

Pain is part of life and the body’s way of communicating that something needs attention urgently. However, in the context of medical procedures such as intravenous prophylaxis, or bleeds that are being treated, this signal serves no useful purpose. It is important to learn ways to minimise the experience of pain and suffering, to avoid the development of anticipatory anxiety, needle phobia, and increased sensitisation to pain. This paper will discuss strategies and resources, with a particular focus on family-centred early intervention to alleviate parental anxiety and maintain the parent-child bond. It will provide guidelines for treating needle phobia.

Impact of bleeding disorders on the family - tools for advocating for your child and family
~ Colleen McKay, Haemophilia Foundation of New Zealand

Inherited bleeding disorders are chronic and lifelong, and their presence will affect all members of the family. Whether there is a family history of a bleeding disorder or not, this diagnosis causes psycho-emotional impact on the parents, as they watch their dream of the ‘perfect child’ slip away. Parents may have multiple feelings which can include shock, disbelief, sadness, disappointment, anxiety, fear, denial, anger, guilt or over-protectiveness, and must work through all of this emotion to emerge as effective advocates for their child and family.

Currently, there is no cure for the bleeding disorder, but there is effective treatment; meaning that parents must adapt in the best way possible to manage the disorder. The task of maintaining a balanced family life, at the same time as providing for the needs of the child with the bleeding disorder and advocating for the child and family in a variety of settings is a huge challenge. Critical coping strategies must be in place and new skills must be learned in order:
• for effective parenting to take place
• to foster the medical, physical, emotional and social growth of all members of the family
• to be an effective advocate for the child with a bleeding disorder, and for the family as a unit
• to ensure adherence to the recommended treatment regimen
It is important that parents take every opportunity to:
• get educated
• get connected
• get organised
• develop a support system
• develop a plan for emergency situations
These crucial strategies will assist parents in their quest for effective family functioning as they undertake the most difficult balancing act; that of maintaining a balanced family life at the same time as providing for the medical, physical, emotional and social needs of the child with the bleeding disorder.

Parents & Health Professionals in Partnership - Improving services in Haematology/Oncology Unit at the Women’s & Children’s Hospital
~ Anne Jackson, Women’s & Children’s Hospital, SA
Sharyn Wishart, Haemophilia Foundation South Australia

The presentation will highlight areas of involvement, the value and benefits for individuals, health professionals and community in providing feedback to improve care and service provision in the health care setting.

It is widely recognised that involving consumers in decision making and development of health information is vital to ensuring that changes and information provision is relevant to individuals and community. The WCH has adopted health promotion as one of the key components of its vision, philosophy, principles and goals. One of the goals of the WCH is to increase effective participation by people in decision making at all levels that affect their or their child’s health. The Haematology/Oncology Unit has undertaken to meet this goal using a variety of strategies. In the haematology/oncology unit, parents and young adults with a chronic illness have been invited to participate in forums to identify and improve the education and information provision of the unit. Parents have been actively involved in the review of health information developed by the unit as a result of parent feedback. Recently a parent advisory committee has been established to work with the unit management to identify areas for improvement and to determine priority for these improvements.

Establishing parent advisory groups in partnership with health professionals and providing opportunities for feedback is crucial to ensuring improvements in care are appropriate and useful with benefits to individuals and community.

Friday 5th October 2007
Positively negative
~ Neil Boal, Haemophilia Foundation Victoria

With haemophilia, arthritis, HIV and hepatitis C, it was hard to know what the main cause of my pain, nausea and flat mood was. I could never really work out what was actually contributing to all of these problems (apart from bleeds and arthritis). Was it all the medications I take for HIV? Or perhaps the HIV itself? Was hepatitis C the culprit, after all I’ve had it since the mid 70’s? Well we really know it’s a combination of all these things. But what impact does each illness have?

I always put more blame on HIV and (to a lesser extent) haemophilia than hepatitis C for my well-being. Besides there wasn’t much we could do about the hepatitis anyway. Sure, interferon came along but was such a drawn out treatment program with awful side-effects and a hopeless success rate it had no appeal to me at all. I got more interested when the current interferon and ribavirin combination became available and was having some success.

It took some personal circumstances to change and a lot of soul searching to finally decide to embark on hepatitis C treatment.

Hepatitis C treatment and care: relevance to haemophilia
~ Prof Geoffrey Farrell, The Canberra Hospital, ACT

The risk of cirrhosis after 20 years of HCV infection is <10% among those under the age of 30 years at the time of infection, slightly higher in men than women. Host genetic factors operating through innate and acquired immune mechanisms are the most important determinants of disease progression; viral factors appear to be irrelevant except in the case of immunosuppression (viral load correlates with disease severity). Other host factors that influence the fibrosis progression rate include chronic excessive alcohol consumption and metabolic factors (overweight, obesity, insulin resistance, type 2 diabetes). The desired outcome of antiviral treatment, “sustained viral response (SVR)” arrests and reverses liver fibrosis, and, with established cirrhosis, prevents liver failure and liver cancer. SVR approximates 50% with pegylated-interferon and ribavirin (PEG-IFN/R), and is influenced importantly by HCV genotype, overweight/insulin resistance and support facilities, to a lesser extent by age, viral load and disease severity (cirrhosis). Alcohol and concomitant HIV infection also reduce SVR, less so if the CD4 count is high and with PEG-IFN/R. The recommended treatment course is 24 weeks for genotypes 2
or 3 (SVR 70-90%), and 48 weeks for genotypes 1/4 HCV (40-50%). A trend is to individualise treatment based on “rapid virus response (RVR)” (PCR negative at 4 weeks). Liver biopsy now plays a less crucial role in case selection; if the HCV-infected person wants treatment it can be offered without prior need to determine histological severity. Conversely, persons not keen to have treatment should reconsider their options if HCV infection is >20 years if there are indications of advanced fibrosis on imaging or laboratory tests. If patient and specialist still prefer to know histological severity of fibrosis, liver biopsy can be performed provided sufficient clotting factor concentrate is administered before the procedure and through day 3.

**Making decisions about hepatitis C treatment: What men are thinking**  
*~ Dr Stephen McNally, La Trobe University, VIC*

Over the past decade there have been significant improvements in treatment for hepatitis C. Despite these improvements, less than 10% of people with hepatitis C have undertaken treatment. While there is good understanding of clinical factors that may enhance successful treatment, very little research has examined the broader social context of treatment to determine what factors may inhibit and facilitate successful clinical treatment.

This presentation is based on a 12-month study involving 224 people living in Victoria with hepatitis C, along with the views about treatment from general practitioners and specialist physicians. It will report on the findings from men with hepatitis C (n= 151). Participants included those who are currently receiving treatment, those who have received treatment in the past, and those who have never received treatment.

Men were more likely than women to be receiving treatment. Participants diagnosed in the past five years were more likely to be receiving treatment compared with those diagnosed more than five years ago.

A range of psychological and social factors have had an impact on the uptake of clinical treatment and impedes or assists treatment adherence for men. The most notable personal, social and treatment issues to influence people’s decisions about proceeding to treatment range from effectiveness of treatment, side effects, impact on work and family, liver status, relationship with doctor/specialist and associated medical problems such as depression.

Study findings provide information on which to base effective health care strategies to assist people in their decisions to take up treatment and to improve the experiences of those who have commenced treatment.
Some practical aspects of laboratory testing for von Willebrand Disorder
~ Geoff Kershaw, Royal Prince Alfred Hospital, NSW

The diagnosis of von Willebrand Disorder (vWD) normally requires three components: a qualitative or quantitative abnormality of von Willebrand factor shown by laboratory tests; a personal history of excessive mucocutaneous bleeding; and a family history of this bleeding tendency. The most commonly performed tests are the measurement of von Willebrand factor antigen, factor VIII coagulant activity, von Willebrand factor ristocetin co-factor activity, and collagen binding activity. Other tests used in conjunction with these are a full blood count, platelet aggregation studies including response to low dose ristocetin and a PFA100 screen. Some specialised laboratories can also perform multimeric analysis and FVIII binding assay to help sub-classify vWD. It is important that laboratories establish their own reference ranges for these tests, as significant variation may occur between methodologies/reagent/analyser combinations. Laboratories should also participate in external quality assurance programs to assess their performance against other testing institutions.

Demystifying the classification of vWD and lessons from the Australian clinical trials
~ Dr Ross Baker, Royal Perth Hospital, WA

von Willebrand Disorder (vWD) is predominately a mucocutaneous and surgical bleeding disorder caused by either a deficient or abnormally functioning von Willebrand factor (vWF). vWF is important in initial haemostasis by securing platelet adhesion to collagen in damaged blood vessels and acting as a carrier for Factor VIII (FVIII).

Laboratory testing allows classification on vWD into 3 main categories by measuring FVIII, vWF antigen and vWF function (ristocetin cofactor, collagen binding assay). Concordant mild decreases in all suggest vWD Type 1, disproportionate decrease in vWF function or FVIII level suggest Type 2 and a virtual absence of vWF antigen suggests Type 3. Subclasses of Type 2 can be distinguished by specialized investigation of ristocetin induced platelet aggregation, multimeric gel electrophoresis and assay for vWF binding capacity of FVIII.

In general the lower the level of vWF (less than 30%), the more likely there is a bleeding tendency which can be identified in a family study using routine
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methodology. Recent analysis suggests a genetic mutation the vWF gene is found in around a half of patients with Type 1 disease and that co-segregation of the gene defect is directly proportional to vWF level.

However Type 1 vWD sometimes is hard to distinguish with confidence because of the continuous and wide distribution of plasma vWF levels and the variation in bleeding tendency in family members with similar vWF levels. It is likely that there are a significant number of people with a mild bleeding tendency and borderline low vWF levels where the diagnosis of Type 1 vWD could be reconsidered in the future. The cause of their bleeding tendency may be multi-factorial and include inheritance of other genetic loci such those coding for platelet receptor expression.

Patients with Type 1 vWD usually respond to desmopressin (DDAVP) whereas those with Type 2 and 3 vWD generally do not. Plasma derived vWF concentrate has been successfully used to treat patients unresponsive to or had an adverse reaction to DDAVP. Different vWF concentrates have different purification and virus inactivation steps and contain various FVIII and vWF antigen and functional ratios. A retrospective analysis of 58 surgical procedures performed with Biostate, a plasma derived factor VIII/vWF concentrate used in Australia revealed excellent efficacy and safety. A mean pre operative dose of 30IU/kg was given to achieve haemostasis. Uncertainty still remains about the laboratory monitoring, dosing frequency and haemostatic response amongst the different vWF types using vWF concentrates.

1 + 1 = 3 - A family experience of vWD
~ Lorraine Porter Bishop, Haemophilia Foundation of New Zealand

When my son Zac was misdiagnosed with haemophilia at 12 months, my partner and I started on a journey that has been fraught with trials and tribulations that we never could have expected or been prepared for - the frustrations of misdiagnosis, the impact on family life of dealing with a chronic illness and the worry of being one of the very few families using plasma based products in a country that is 100% recombinant for all children.
Building relationships – effective communication and telling partners about bleeding disorders and blood borne viruses
~ Dr Sarah Martin, The Canberra Hospital, ACT

Telling a partner that you have haemophilia can feel hard enough. Telling a partner that you also have HIV or hepatitis C can feel even harder. Working out when to tell, how to tell, wondering about how they will react and whether you will be rejected can all be very stressful. It might put you off intimate relationships altogether or you might have found yourself in situations where you wish you had said something earlier. On the other hand, you might already have found that being open about yourself brings two-way trust and honesty so that you can concentrate on all the fun parts of relationships. There are things we can do when we need to talk about our health: tune in to the need to talk, think about possible reactions, get up-to-date with questions a partner might ask like treatment, safer sex, having children or even legal issues, make a plan to tell them, get support, and perhaps have a practice run. Friends, family and health care workers can provide helpful advice and support. This session draws on the experiences of young people with haemophilia and blood borne viruses to look at communication in intimate relationships. Laboratories should also participate in external quality assurance programs to assess their performance against other testing institutions.

Better health and fitness: laying the foundation for positive and independent management of haemophilia
~ Brendan Egan & Janine Furmedge, Royal Children’s Hospital, VIC

Management of haemophilia in the early years is critical in reducing the impact of the condition on both the family and on the individual in the future. This session will discuss programs that empower families to be proactive about their child’s experiences and support a positive approach to haemophilia management.

Establishment of early home therapy allows prevention of bleeding episodes, preservation of joint function and independence from hospital based treatment. Normalisation and inclusion in school and extracurricular activities is promoted. Self infusion and participation in school camps is an important step towards independence and promotion of self esteem.
As we provide these early positive educational experiences we hope that the child will have the foundation for good management practices that will persist into adolescence and adulthood. This will reinforce the appropriate management of bleeding episodes, but hopefully more importantly will ensure appropriate sport and leisure choices that will continue to have benefits for the child for years to come. Our goal is to have our group of patients independent by the time they are transitioned at the end of school.

Making the Move: There is planning and there is what actually happens!
~ Leonie Mudge, Royal Prince Alfred Hospital, NSW

This session will outline the components to be considered when planning for the transition of young people with bleeding disorders from a paediatric setting to adult facilities. Consideration will be given to the perspective of
1. health care professionals
2. parents and carers, and of course
3. the young people themselves.
There will be particular discussion about lifestyle health and career planning.
Fitness and physical activity in children with haemophilia

~ Dr Carolyn Broderick, University of New South Wales, NSW

The past three decades have seen a dramatic change in the advice given to children suffering from haemophilia. Prior to the 1970s children were strongly advised to avoid sports participation for fear that it may lead to bleeds into joints and muscles. Today, widespread use of prophylactic factor concentrates has enabled children with haemophilia to return to sport but advice to perform structured exercise has not been part of routine management. One likely consequence of this is that children with haemophilia are less fit and strong compared to their healthy peers. This finding has been supported by current research.

Recently, it has been suggested that regular physical activity may reduce the risk of bleeding episodes. This may occur because stronger muscles are better able to protect the joints and improved co-ordination and motor skills developed through regular physical activity may lessen the risk of falling.

Most parents are aware of the beneficial role of physical activity in the life of children but, in children with haemophilia, these benefits need to be balanced with the possibility that physical activity may trigger a bleeding episode, which, if recurrent, can result in permanent joint damage with resultant pain and disability.

Our current studies in NSW are aimed at answering 4 important questions regarding physical activity and sport in children with haemophilia:
1. Are children with haemophilia less fit than their healthy peers?
2. Does a structured exercise program of 3 months duration improve fitness and quality of life in children with haemophilia?
3. Is there a transient increase in the risk of bleeding associated with exercise in children with haemophilia, and if so can we quantify this risk?
4. Does regular physical activity modify the risk of bleeding?

This presentation will provide an overview of our exercise studies. We believe that our findings will enable health professionals to better advise children with haemophilia and their parents about safe physical activity and participation in sport.
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**Strategies to promote healthy participation – overcoming the barriers**  
~ Wendy Poulsen and Salena Griffin, Royal Children’s Hospital, QLD

There are many physical and psychological reasons that impact on a person’s ability or willingness to participate in sporting activities or exercise. Often many of the barriers and fears that people have are a result of misinformation. Before the era of prophylaxis regimens, the life of a person with a bleeding disorder was to a great extent dependent on the severity of the condition, and the frequency of bleeding episodes. This often resulted in long periods of hospitalisation and an inactive lifestyle. The introduction of factor replacement, home treatment and prophylaxis has made it possible for people with bleeding disorders to live a life in which participation in sports and leisure activities is now possible.

**Auckland Islands sea kayak adventure……………. “Bloody Can Do It”**  
~ Jack Finn, Haemophilia Foundation of New Zealand

Jack Finn is a young adventurer who lives with mild haemophilia and hepatitis C. His presentation will entertain with his latest adventure of solo sea kayaking around the sub-Antarctic Auckland Islands, to educate people about haemophilia and raising awareness. Jack has made a big impact on the New Zealand public through much media attention and continues to do so with his established profile.

Jack’s presentation is a story of human determination, adventure and shows someone who’s getting out there and charging ahead with life. The talk will include a combination of photographic still photos and video.

*Friday 5th October 2007*
FRIDAY 5 OCTOBER 2007
1530-1700
PLENARY 2 - YOU WON'T DIE FROM LAUGHING
Room: Federation Ballroom
Chair: Patricia Cameron-Hill and Shayne Yates, Cameron-Hill & Yates
Seminars: Australia

Practical ideas on how to have less stress in your life, boost your sense of humour and live longer!

Patricia Cameron-Hill BA App Sc and Dr Shayne Yates MBBS are world experts on stress and humour. Their careers as a nurse and doctor give them a special understanding of stress, its consequences and its cure.

They balance the funny side of stress with the serious side by including strategies for resisting and reducing stress.

They are well known for their best-selling book “You won’t die laughing”.
www.chy.com.au
Individualisation of prophylactic treatment of severe haemophilia: when to start and when to stop
~ Dr Kathelijn Fischer, Department of Haematology, UMCU, Utrecht

The timing of the initiation of prophylaxis is an important issue: the long-time experience from the Swedish group has shown that early prophylaxis can prevent bleeds and subsequent joint damage. Rather than starting at a fixed age, starting prophylactic treatment is increasingly individualized according to patient characteristics. One of the arguments in favour of an individualized approach is the large variability of bleeding patterns in patients with severe haemophilia; this is reflected by the variation in the age at first joint bleed, ranging from 0.2 to 5.8 years. It has been suggested that arthropathy was best prevented if prophylaxis was started before the second or third joint bleed. It has been reported that arthropathy on X-ray at age 19 years was 8% increased (95% CI 1-16%) for every year prophylaxis was postponed after the first joint bleed. Since then, many have studied other potential indicators of bleeding patterns, but the age at first joint bleed currently remains the most promising parameter.

Although the WHO has advised continuing prophylaxis throughout life, tapering or discontinuing prophylaxis in adults is part of individualisation of treatment.

Studies from Denmark and the Netherlands reported that 35% of patients discontinued prophylaxis around the age of 21. These patients were all treated with early prophylaxis, but were characterized by a milder bleeding pattern than the patients who continued prophylaxis. However, the long-term effects of discontinuing prophylaxis in patients with milder bleeding patterns should be studied before becoming standard treatment.

In conclusion, while it is well established that prophylaxis reduces the annual number of joint bleeds, the optimum prophylactic regimen is still under debate. Especially the start of prophylaxis is an important determinant of outcome. However, the prophylactic regimen may be individualised according to bleeding pattern, including aspects of start and duration of treatment. In addition to reducing the burden of treatment, this approach may increase efficiency of this expensive treatment.
Pre-genetic diagnosis/reproductive technologies
~ Dr Penelope Foster, Melbourne IVF, VIC

Pre-implantation genetic diagnosis for haemophilia offers couples at risk of transmitting the condition the possibility of determining the status (affected or unaffected) of an embryo before transferring it for possible pregnancy, as an alternative to antenatal testing and the termination of an affected pregnancy. Patients may choose sex-selection or specific gene detection, and undergo an IVF treatment cycle to develop embryos suitable for testing. Outcomes from PGD are good, but the treatment is expensive and not without pitfalls.

Patients with HIV may be interested in the program developed at the Chronic Viral Illness Clinic at the Royal Women’s Hospital, Melbourne, which offers fertility treatment to the female partners of HIV+ men. The male needs to have undetectable viral load in blood and semen; screened semen is stored and used for IVF or IUI (intra-uterine insemination) in the female partner.
Vascular disease in haemophilia

~ A/Prof Alison Street

Sarah Darby and colleagues have recently published on the causes of mortality in patients with haemophilia in the UK, not infected with HIV. They reported a decrease in the incidence of coronary artery disease compared with the general population. The death rate due to stroke secondary to arterial disease between haemophilia and non-haemophilia patients was the same.

No such data have been studied in Australia though similar findings of reduced death rates due to coronary artery disease have also been reported from smaller studies from The Netherlands and Greece. Of interest there is no reduction in the incidence of hypertension or hypercholesterolemia in the haemophilia population compared with normal and the incidence of renal disease which predisposes to hypertension is increased in haemophilia.

Nonetheless patients with haemophilia may still present with symptoms of myocardial ischaemia. Management with thrombolytic therapy is not routinely recommended because of the bleeding risk in sites of recent or recurrent haemorrhage. Alternative therapy with percutaneous coronary angioplasty is often preferred which will require subsequent anti-platelet therapy as tolerated.

Coronary artery bypass grafting and other revascularisation procedures require careful planning between surgical and haemophilia teams.

More studies are required into the evidence for, causes, outcomes and preventive strategies necessary to reduce the incidence of atherosclerotic incidence of vascular disease in our ageing haemophilia population.

1 Mortality rates, life expectancy, and causes of death in people with haemophilia A or B in the United Kingdom who were not infected with HIV. Darby et al, Blood, 2007; 110, 815-825.
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Chronic haemophilic arthropathy
~ Prof John York, Royal Prince Alfred Hospital, NSW

Advances in haemophilia care have impacted the management of haemophilic arthritis. The development of purer factor replacement materials and more recently the availability of recombinant factor VIII and IX has made it possible to commence boys on prophylactic treatment as soon as practicable after diagnosis. The almost inevitable onset of joint disease in severe haemophilia is now mostly preventable.

Major advances include the concept of team management in specialised haemophilia centres, opportunities to play sport with reasonable safety, the use of radioactive isotopes to control synovitis and bleeding, joint replacement surgery particularly for the knee and elbow, available anti-viral therapy for HIV1 and hepatitis C, more adequate measures to combat inhibitors, and the sadly still elusive prospect of gene therapy.

However, remaining hurdles pose unsolved problems such as the frequency of ankle joint involvement and the inadequacy of current surgical options, the management of von Willebrand Disease, low factor levels in some carriers, pain control in severely affected arthritic people and the inevitable onset of degenerative joint disease, unrelated to haemophilia, as treatment increases longevity.

The greatest challenge posing very different dilemmas both for developed and developing countries in the world is the mal-distribution of available treatment so that 80% of the world’s sufferers do not have access to any treatment.

Falls and balance – from research to practice
~ Marcia Fearn & Prof Keith Hill, National Ageing Research Institute, VIC

Falls are a common problem in older people generally; however balance dysfunction and falls have rarely been reported in the research literature for people with haemophilia and other bleeding disorders (PWH). Research has shown that identifying and managing risk factors for falls can be effective in reducing falls rates. Exercise, especially exercise that focuses on balance, has been reported as an effective and successful approach to improving balance and preventing falls in older people. A project funded by Haemophilia Foundation Australia, and conducted jointly between the National Ageing Research Institute and staff of the Ronald Sawers Haemophilia Centre at the Alfred Hospital evaluated the level of balance dysfunction in PWH, and the effectiveness of a home exercise balance program. Twenty PWH and other bleeding disorders, and 20 age matched healthy controls were recruited. The average age of the PWH was 39.4 (12.3), 50% reported one or more falls in the preceding 12 months, and 90% had moderate or severe haemophilia. Testing on a variety of simple clinical measures of balance, mobility, and confidence,
and balance measures on a state of the art force platform, indicated moderate levels of balance problems across a range of balance related tasks for the people with haemophilia and other bleeding disorders. A physiotherapist prescribed a balance training program to be conducted at home for the PWH group, for a duration of four months. Twelve participants completed the home exercise program and returned for re-assessment. There were improvements of between 5-20% on most of the balance measures after the exercise program, although only one of these was statistically significant, given the small sample size. These results suggest that measures of static and dynamic balance performance should be considered in the physical assessment of PWH, and that where reduced balance is present, physiotherapists should include balance training in addition to more routinely using strengthening and flexibility exercise approaches. A simple balance assessment test battery, and factors influencing clinical decision making regarding exercise prescription in this study will be discussed.
Hepatitis C and young people
~ Vicki Jermyn, The Children's Hospital at Westmead, NSW

Hepatitis C is a blood borne viral infection, which is transmitted through infected blood entering another person’s blood stream and causing inflammation of the liver. Transmission of the virus can be caused by activities such as sharing IV drug injecting equipment, non-sterile tattooing or body piercing and needlestick injuries. Hepatitis C can be transmitted from mother to baby during pregnancy and is also reported as the result of the transfusion of blood products prior to 1990. Thus children and young people may be affected as well as adults. Signs and symptoms can appear a long time after exposure to the virus and can vary from mild to severe and the majority of children have little or no symptoms of the disease. However, the diagnosis of hepatitis C presents many issues and challenges for the young person and their family, particularly if they are already dealing with other medical conditions such as bleeding disorders. These include the practical aspects of treatment options, side effects and monitoring, the psychosocial aspects of self care, education and safety and the community concerns of disclosure, discrimination and exclusion. This paper will provide an overview of hepatitis C in young people, discussing treatment options and focusing on the many challenges facing young people and their families.

Hepatitis C related stigma and discrimination - origins, impacts and responses
~ Helen Tyrrell, Hepatitis Australia, ACT

Hepatitis C related stigma and discrimination is the additional burden imposed on people with chronic hepatitis C by society. The 3D Project conducted by the National Centre for HIV Social Research, NSW (NCHESR) revealed widespread discrimination involving a variety of sources including family, friends, health care workers and employers. The C-Change report by the Anti-Discrimination Board of NSW found that health care settings were the most commonly reported context for hepatitis C related discrimination.

This is a burden which those living with many other chronic diseases do not experience.

This paper will explore the nature of stigma. Drawing on the seminal work by Irving Goffman it will explore how the stigmatised person feels as a result of being disqualified from social acceptance on the basis of their disease or
behaviour. The specific origins and impacts of hepatitis C related stigma will be explored.

The media, those affected by hepatitis C, health care workers and the general public all play a role in either adding to or breaking down stigma. Is stigma just part of life for the person with hepatitis C or can we change societal attitudes to health, illness and injecting drug use?

The roots of hepatitis C related discrimination can be found in stigma. Fear of contagion and stereotyped responses to presumed injecting drug use clearly drive discrimination. The Ottawa Charter for Health Promotion provides a useful framework for examining the required responses to reduce the burden of hepatitis C related stigma and discrimination into the future.

Experiences of the bleeding disorders community with hepatitis C
~ Suzanne O’Callaghan, Haemophilia Foundation Australia

Many people with bleeding disorders acquired hepatitis C from blood products before testing was introduced in 1990 and have now been living with hepatitis C for more than 20 years. What are their current needs in relation to hepatitis C? What are the needs of their partners, families and carers? Haemophilia Foundation Australia recently undertook a national needs assessment in order to develop its national hepatitis C strategy. This involved following up a community hepatitis C survey from 2003 by conducting focus groups with people with bleeding disorders affected by hepatitis C and their partners, families and carers and consulting with state and territory Haemophilia Foundations and haemophilia and hepatitis health professionals. This looked at current health, experiences with hepatitis C care and treatment, the psychological impact, relationships, disclosure, stigma and discrimination, working and financial issues. Haemophilia Foundations and health professionals expressed concern that a large proportion of people with bleeding disorders who had initially been diagnosed hepatitis C antibody positive did not appear to know their current hepatitis C or liver health status. Focus groups confirmed the difficulties people had in understanding their current health and with monitoring and treatment. Some did not have symptoms and felt hepatitis C was peripheral to their lives. By the age of 35-40 years, others found the combination of their bleeding disorder and hepatitis C had a major effect on their ability to work and their finances, home and social lives. For younger people, hepatitis C loomed large in their relationships, working life and social activities.
Mothers, partners, carers, people with bleeding disorders and carriers of the haemophilia gene
~ Belinda Burnett, Using genetic counselling services TBC

Menorrhagia: best care and practice
~ Dr Julia Phillips, Wellington Hospital, NZ

Menorrhagia (heavy menstrual bleeding) is a major health problem that often goes unrecognised by patients and doctors alike. Menorrhagia affects at least 5-10% of all women at some stage in their life (Oehler 2003, Vessey 1992). Congenital bleeding disorders are found in up to 20% of women suffering menorrhagia (Shaw 1994). The most common of these is von Willebrand Disorder (vWD), in which approximately 90% women are affected by heavy menstrual bleeding (Fraser 1994). A thorough personal and family bleeding history is important in identifying women with menorrhagia who are likely to have bleeding disorders. Testing for congenital bleeding disorders in the laboratory is complex and does not always provide a definitive diagnosis, particularly in mild vWD. Effective non-surgical treatment options are available for menorrhagia in women with normal coagulation. However, there is a little information on the benefits of such treatment in women with bleeding disorders. Surgical approaches include endometrial ablation and hysterectomy. Collaboration between family doctors, gynaecologists and haematologists is important for the provision of good health care for women with bleeding disorders. Optimal diagnostic algorithms and clinical management strategies for women with bleeding disorders and menorrhagia remain to be determined and well-designed clinical trials in this area are needed.

Fraser IS. Br J Obstet Gynaecol. 1994;101 (suppl 11):3-7

Management of delivery in carriers and management of the newborn
~ Dr Susan Russell
(Abstract unavailable at time of print)
The measurement of physical activity in boys with severe haemophilia

~ Brendan Egan, Royal Children’s Hospital, VIC
(Co-Authors; Dr Chris Barnes, Dr Bev Eldridge, Dr Rory Wolfe)

In the past boys with haemophilia were discouraged from participating in physical activity. The introduction of prophylaxis has allowed these boys to experience less bleeding episodes and participate in a wide variety of sporting and leisure activities. Currently there are no quantitative measurements of physical activity in the haemophilia population.

The PAL-1 is a remote activity monitor that records uptime (time spent in the upright position). Uptime is an indication of physical activity and normative values for the general child population (age 8-15 years) are available.

The aim of this research was to measure uptime in a group of boys with severe haemophilia. Total uptime for each 24-hour period of recording was used to calculate mean uptime. This was compared to the mean uptime in normal children in order to investigate whether boys with severe haemophilia were less active than their peers. Fourteen boys with severe haemophilia were recruited from the Haemophilia Treatment Centre to participate in the study. They wore the PAL-1 for a maximum of four consecutive days.

The results showed that boys with severe haemophilia had a mean uptime of 4.9 hours per 24-hour period (SD 1.3, range: 2.0-8.2 hours) compared with 5.3 hours (SD 1.5, range: 1.5-10.3 hours) for male children in Victoria, Australia. There was no significant difference in within- and between-child variability in uptime compared to normative values. The conclusion was that boys with severe haemophilia are as active as their peers and that uptime is a useful outcome measure for this group of children.

Workshop for young women and bleeding disorders

~ Colleen McKay, Haemophilia Foundation of New Zealand

Traditionally, little attention has been given to women affected by bleeding disorders. Given their significant role within the bleeding disorders community, HFNZ has undertaken a variety of strategies to ascertain the needs of affected women, support them, and help them to realise their full potential. One such strategy was the implementation of a Young Women’s Weekend Workshop (YWWW).

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YWWW has three main objectives: (1) to provide participants with information and education, thus empowering participants to make informed choices for their health care now, as well preparing them for the future; (2) to provide the opportunity for participants to work through the issues associated with their condition; and (3) to develop a sense of community within the group, so that participants and other young women could form a support network to help them to encourage each other as they overcome the barriers created by their bleeding disorders.

Women living in New Zealand aged between 13-30 years with von Willebrand Disorder or who carry the haemophilia gene were invited to attend a weekend workshop in August 2005. Carefully developed to ensure that all activities would fit with the Objectives, Education Sessions were interspersed with Recreational Activities to ensure that the Program was fun, while keeping participants engaged.

In total, 22 young women attended the Young Women’s Weekend Workshop, 18 who carried the haemophilia gene and 4 with von Willebrand Disorder. Evaluation revealed the initiative met all three objectives. The Education Sessions scored particularly high, especially those on Reproductive Choices and Lifestyle issues.

Participants clearly valued the opportunity to meet others facing similar challenges and feel less alone. With a far greater understanding of how their disorder can affect them, they are more confident about how it can be managed.

Attitudes towards and beliefs about genetic testing in the haemophilia community, a qualitative study
~ Dilinie Herbert, Monash Centre for Ethics in Medicine and Society, VIC (Co-Authors; Prof Alison Street, Prof Agnes Bankier, Dr Chris Barnes and Julie Boal)

Widespread genetic testing for haemophilia has recently been introduced in Victoria. While attitudes towards predictive testing have been studied in other conditions, such as cancer, there is limited knowledge about the attitudes of members in the haemophilia community towards predictive testing. This study was aimed at exploring attitudes towards, and beliefs about, genetic testing amongst members of the haemophilia community in Victoria prior to the widespread introduction of testing. The study was qualitative and descriptive. In-depth face to face interviews were conducted with a sample of 39 individuals, including men with haemophilia, female carriers and family members. Data were analysed thematically using cross case analysis techniques.

There was considerable knowledge about the proposed introduction of widespread genetic testing. However, not everyone thought that testing was
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accessible or user friendly, and there was confusion about who needed to be tested. Most thought that testing was necessary for adolescent girls to determine carrier status to help prepare families for a child with haemophilia, rather than leading them to choose to terminate a pregnancy or not to have children. A minority of women stated that if there was a history of inhibitors in a family then a termination might be considered. Several people also mentioned that timely antenatal genetic testing may facilitate better obstetric care. The study revealed strong religious beliefs among those studied, which may have influenced attitudes and approaches towards testing. Further investigation is needed into how people with a possible haemophilia genotype negotiate decisions about their further identification, and how this knowledge is placed within cultural, religious and family contexts.

A retrospective study of the utility of the 1-deamino-8-D-arginine vasopressin (DDAVP) trial in the management of patients with von Willebrand Disorder
~ Dr Jake Shortt, The Alfred, VIC
(Co-Authors: Stephen S Opat, Malgorzata B Gorniak, Heather A Aumann, Margaret F Collecutt & A/Prof Alison Street)

DDAVP is effective in securing haemostasis in selected patients with von Willebrand Disorder (vWD) undergoing haemostatic challenge. Due to the heterogenous response to DDAVP, it is currently recommended that patients with vWD undergo a therapeutic trial prior to elective surgical procedures. In order to determine which patient groups most benefit from a DDAVP trial, we performed a retrospective analysis of DDAVP trials for vWD at our institution between 1990 and 2006.

We identified 129 patients with a bleeding history and a prior diagnosis of vWD based on low von Willebrand factor antigen (vWF: Ag), ristocetin cofactor assay (vWF: RiCof) or collagen binding assay (vWF: CBA). Twenty-one patients were excluded due to having normal vWD parameters prior to DDAVP. DDAVP was administered by iv infusion with samples collected at baseline and between 1 and 2 hours post-administration. Additional testing at 24 hours was performed in the majority of patients after 2003.

Responses to DDAVP were defined as complete (CR) if all vWD parameters (vWF: Ag, vWF: RiCof & vWF: CBA) increased to the normal range, or partial (PR) if they increased to between 30% and the lower limit of normal.

All type 1 patients with baseline vWD parameters ≥20% responded at 1 hour (55/57 patients with CR, 2/57 with PR). Only 2/6 type 1 patients with either a baseline vWF: Ag or vWF: CBA <10% responded. All patients with a mildly reduced vWF: RiCof in isolation achieved CR and had adequate (>30%) levels at 24 hours. Of the 18 type 1 patients who had testing performed at 24 hours, 11/14 with an initial CR had adequate levels at 24 hours but none of 4 with
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diagnoses. 9 (10%) developed end-stage liver disease, of whom 7 subsequently died. Development of AIDS end stage liver disease and HIV related deaths all declined markedly following the introduction of HAART.

Clinical and psychosocial outcomes were assessed in the 38 survivors. 33 (85%) were receiving HAART, with one patient remaining on single agent therapy. The median current CD4 count was 429 cells/μL (range 23 to 943), and median CD4 nadir 113 cells/μL (range 1 to 400). The median current viral load was <50 copies/mL (range <50 to >100000). Of survivors, 8 (21%) had developed an AIDS-defining illness. 8 had received treatment for HCV; 2 had end-stage liver disease. Psychosocial indicators in survivors were favourable, with 22 (58%) employed or studying, and 21 (55%) in a long-term relationship, while 13 (34%) had offspring.

Conclusions: This review demonstrates the profound impact of HIV on the lives of these patients, the remarkable impact of antiretroviral therapy, and the personal resilience of the group.

The safety and efficacy of enfuvirtide therapy for HIV infection in patients with haemophilia
~ Dr Mark Polizzotto, The Alfred Hospital, VIC
(Co-Authors A/Prof Alison Street, Dr Edwina J Wright)

Background: The emergence of new classes of antiretroviral agents may have particular significance for patients with congenital bleeding disorders who are infected with HIV, for whom existing therapies are commonly ineffective or poorly tolerated. Enfuvirtide is the first of a new class of antiretrovirals, the viral entry inhibitors. Its use in patients with haemophilia has not previously been described. We present our experience with enfuvirtide in patients with HIV and severe haemophilia A.

Methods: Demographics and medical history were obtained retrospectively from patients’ case records

Results: Four patients were treated, ranging in age from 27 to 51 years. Each was coinfected with Hepatitis C; one had end-stage liver disease awaiting hepatic transplantation. Three had suboptimal response to and/or unacceptable toxicity from their existing antiretroviral regimens, while one had previously ceased all antiretrovirals by personal choice. They had previously received a median of 4 lines of combination antiretroviral therapy (range 3 to 5). All had resistance to multiple antiretroviral classes identified on mutation testing. CD4 counts ranged from 135 to 365 cells/μL prior to the introduction of enfuvirtide, with HIV viral loads ranging from 900 to >100000 copies/mL.

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Enfuvirtide was introduced in combination with optimised antiretroviral therapy. Patients received education in its use prior to commencement. Each achieved a sustained virological and immunological response with enfuvirtide-containing regimens, with three achieving undetectable viral loads following six to twelve months of therapy, and an increase in CD4 counts to between 245 and 350 cells/µL.

Enfuvirtide was generally well tolerated. The major side effect reported was local skin reactions including thickening; two patients also experienced local bruising at the subcutaneous injection site. No increase in the rate or severity of systemic bleeding was apparent, even in those patients with high rates of bleeding and in the two patients who were not receiving prophylactic coagulation factors. One patient fell while injecting himself with enfuvirtide, sustaining a fractured femur which necessitated a prolonged inpatient stay.

Conclusions: This is the first reported use of enfuvirtide in patients with haemophilia and HIV. It demonstrates that enfuvirtide as part of optimised antiretroviral therapy can be an effective, well tolerated treatment option for these complex patients.

Blood, toil and tears: clinical and psychosocial outcomes over 25 years in patients with haemophilia infected with HIV

~ Dr Mark Polizzotto, The Alfred, VIC

(Co-Authors; Leonie Mudge, Megan Walsh, Penelope McCarthy, Dr Edwina J Wright, Dr Joseph Sasadeusz, A/Prof Alison Street)

Background: During the early 1980s, many patients with haemophilia were infected with HIV through contaminated plasma derived clotting factors. The impact of this has not been reported in an Australian context.

Aims: To review clinical and psychosocial outcomes of Victorian patients with haemophilia over the 25 years since infection.

Methods: Identification of all patients diagnosed with HIV, with retrospective review of major clinical outcomes including progression to AIDS-defining illness and mortality stratified by cause to 31 December 2005. For those alive at that point, additional review of psychosocial outcomes.

Results: 90 patients seroconverted between June 1980 and December 1984, at a median age of 17 (range 1 to 64). All were subsequently also found to be HCV infected. None was lost to follow-up.

52 patients (57%) have died. HIV was the cause of 29 deaths (56%), liver disease including HCV 9 deaths (17%), and haemorrhage related to the underlying bleeding diathesis 3 deaths (6%). 36 (40%) developed an AIDS-defining illness, of whom 28 subsequently died. The major AIDS defining illnesses...
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were pneumocystis jiroveci (PCP), candidiasis and cryptococosis (together 80% of diagnoses), while PCP, mycobacterium infection and malignancy were the major HIV related causes of death (together 70% of diagnoses). 9 (10%) developed end-stage liver disease, of whom 7 subsequently died. Development of AIDS end stage liver disease and HIV related deaths all declined markedly following the introduction of HAART.

Clinical and psychosocial outcomes were assessed in the 38 survivors. 33 (85%) were receiving HAART, with one patient remaining on single agent therapy. The median current CD4 count was 429 cells/µL (range 23 to 943), and median CD4 nadir 113 cells/µL (range 1 to 400). The median current viral load was <50 copies/mL (range <50 to >100000). Of survivors, 8 (21%) had developed an AIDS-defining illness. 8 had received treatment for HCV; 2 had end-stage liver disease. Psychosocial indicators in survivors were favourable, with 22 (58%) employed or studying, and 21 (55%) in a long-term relationship, while 13 (34%) had offspring.

Conclusions: This review demonstrates the profound impact of HIV on the lives of these patients, the remarkable impact of antiretroviral therapy, and the personal resilience of the group.
Managing arthritis
~ Arthritis ACT

Dealing with depression
~ Dr Paul Denborough, The Alfred, VIC

Medical illness is associated with a 4% higher prevalence rate of psychiatric disorders and a 28% higher lifetime prevalence. Depression is the most common of these disorders.

There is a fundamental similarity in psychological status among patients with different chronic physical illnesses and severity rather than type of illness.

Coping with the illness often depends more on enduring personality constricts and family factors.

When chronic illness like haemophilia interact with adolescence and normal developmental processes it can be difficult for teenagers and their families to know the best way to cope.

This talk will focus on some of the issues that haemophilia brings to families and how to try and deal with them.
Using data for good clinical outcomes (ABDR)
~ Dr Ross Baker, Royal Perth Hospital, WA

The Australian Bleeding Disorder Registry (ABDR) was established by AHCDO under the Commonwealth Quality Assurance legislation for the collection of data for haemophilia care in Australia. It provides de identified aggregate analysis of demographic data and product use from all states in Australia.

Around 3,499 patients are registered from the 15 Haemophilia Treatment Centres. There are 1385 people with haemophilia A (510 severe) and 330 people with Haemophilia B (75 severe). Adults (>18 years of age) with severe haemophilia A or B have either hepatitis C (85%) or HIV infection (23%). No child has newly diagnosed infection. All HIV people with haemophilia are co-infected with hepatitis C. 13% of people with haemophilia A have developed an inhibitor.

Product use amongst people with severe haemophilia accounts for more than three quarters of the concentrate used. The mean dose of factor concentrate for severe haemophilia A is 253,000IU/year and for haemophilia B is 188,124IU/year which is similar to other developed countries. The use of recombinant FVIII and rFIX accounts for 95% and 74% of product used respectively. Around 70% of children less than 18 year of age with severe haemophilia use prophylaxis.

This is the first time that this sort of information for haemophilia care is available in Australia. The ABDR provides the haemophilia community, haemophilia health providers, government and suppliers of blood products reliable information to improve the provision of haemophilia care. It can highlight differences in international practices and offers a facility to demonstrate improvement in clinical outcomes and quality of life for people with bleeding disorders in Australia.

The NBA four years on - focus on patient needs, achievements and future opportunities
~ Dr Alison Turner, National Blood Authority, ACT

The National Blood Authority was established in 2003 to improve and enhance the management of the Australian blood and blood products. The NBA's role is to coordinate national demand and supply planning of blood and
blood products and to purchase and manage the blood supply on behalf of all Australians.

Four years on, the NBA is now firmly established as a critical part of Australia’s blood sector, with a growing international reputation. More importantly though, we have been able to deliver for people with haemophilia, access to the best products in the world at a lower cost to governments than under previous arrangements. NBA has established processes which optimise supply management and maintain a strong focus on effective supply planning and monitoring of products to ensure we continue to provide the products that are needed.

This was demonstrated over the last 12 month period when domestic plasma-derived factor VIII was in short supply for much of the year. The NBA worked with AHCDO to manage this problem and part of the solutions was a unique contractual arrangement for the supply of an imported product in the event that we need it.

Over the last year, the NBA has been working closely with HFA and AHCDO to improve knowledge of bleeding disorders, by the re-development of the Australian Bleeding Disorder Registry (ABDR). The aim of this re-development is to better meet individual stakeholder needs in a contemporary IT environment. The new system aims to provide complete and accurate clinical, treatment, product and demographic information on people with bleeding disorders, while respecting the privacy of patients. The information will be used to improve clinical treatment and the management of demand and supply. The NBA would like to thank the huge number of stakeholders, including the HFA, who have willingly provided their time and ideas to contribute towards the development of the specifications of the proposed system.

Blood products for the treatment of haemophilia: priorities for government
~ Roderick Saunders, Blood & Organ Donation Strategy Section
Blood, Organ and Tissue Policy Branch of Department of Health and Ageing, ACT

Under Australia’s national blood arrangements, the responsibility for funding and policy-making is shared by the Commonwealth and all State and Territory governments. This presentation will outline key issues and priorities for governments, the Commonwealth Government in particular, with a focus on the provision of plasma-derived and recombinant products for the treatment of clotting factor deficiencies.

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The presentation will give an overview of the findings and conclusions of Review of Australia’s Plasma Fractionation Arrangements that was conducted in 2006. Aside from the central question of options for future fractionation arrangements, a number of the review’s recommendations were directed at increasing plasma collection rates and improving the effectiveness of the national blood arrangements. A workplan to address blood sector issues that were identified in the recommendations has been a matter for governments’ attention during 2007.

While intravenous immunoglobulin (IVIg) is expected to continue to be the main driver of demand for plasma products, the review predicted that there will be some increase in demand for plasma-derived clotting factors VIII and IX over the next ten years. The presentation will explain the methodology that was used in modelling future demand for products. It will also examine supply and demand trends for both recombinant and plasma-derived factor replacement therapies, and current and emerging issues in the plasma fractionation sector.

In summary, the presentation will give an overview of some current issues from a government perspective in working towards the goals of a safe, secure, adequate and affordable supply of blood and blood products.

Safety of haemophilia products - keeping ahead through regulation
~ Prof Albert Farrugia, Therapeutic Goods Administration, ACT

The safety and efficacy of haemophilia concentrates requires constant vigilance and allocation of regulatory attention in the areas which yield the highest value. In this presentation the evolution of the current generation of products will be reviewed through a series of case studies focussing on the determinants of safety.
SATURDAY 6 OCTOBER 2007
1530-1650
PLENARY 4 - CONFERENCE CLOSING... AND WHAT ABOUT THE FUTURE?
Room: Federation Ballroom
Chair: Dr Scott Dunkley, Royal Prince Alfred Hospital, NSW

Panel:
Dr Chris Barnes, Royal Children’s Hospital, VIC
Dr Kathelijn Fischer, Department of Haematology, UMCU, Utrecht
Prof Albert Farrugia, Therapeutic Goods Administration, ACT
1. Overall
How would you rate the 14th 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 Reception
How would you rate the Welcome reception?
(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)?

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7. What additional topics would have improved the Program?
(Please list your suggestions)

8. Hotel and meeting rooms
How would you rate the Hyatt 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!