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HAEMOPHILIA FOUNDATION AUSTRALIA

www.haemophilia.org.au

MESSAGE FROM THE CHAIR... Paul Bonner

The Youth Committee has been very busy over the past few months finalising the Youth training weekend to be held next month in Tasmania. I am happy to say that we have 19 participants from around Australia and varying in ages. We will provide you feedback in the next edition of Youth News.

Following is an overview of the International Hemophilia Congress. For more detailed information read *National Haemophilia* or visit World Federation of Hemophilia website www.wfh.org.

HEMOPHILIA 2006 WORLD CONGRESS, VANCOUVER

~ SOME HIGHLIGHTS FROM THE VANCOUVER CONGRESS PROGRAM ~

✂ *Treatment for All*

WFH vision is *Treatment for All* – did you know that 70% of people with haemophilia throughout the world have not been diagnosed and only 25% receive adequate treatment?

You do know that with proper treatment, as we know it in Australia, people will live longer healthy lives. We need to find ways for more people around the world to access treatment and get the chance that we have to live normal, active lives.

✂ *A Cure for haemophilia?*

We all hope for a cure for haemophilia – but it will be some time before research becomes a reality – gene therapy promises hope for the future but it must be safe, accessible and cost effective – we need more clinical trials but these must be safe for patients.

✂ *Orthopaedic surgery for inhibitor patients*

More surgery for people with haemophilia, including people with inhibitors, although the outcome may not be as good in people with inhibitors.

✂ *Prophylaxis*

Prophylaxis is important in preventing development of joint damage – but still many challenging questions – when should you start, what should the dosage be and should you stop in adulthood?

✂ *Why do people develop inhibitors?*

There was discussion about why inhibitors develop and whether they develop more often in people using recombinant clotting factor compared to plasma derived factor. There may be a difference, however more research is needed to understand this better.

✂ *New Therapies in development*

Wouldn't it be good to have a clotting factor that lasts longer in your body so you don't have to give yourself infusions so often?

✂ *Other Bleeding Disorders*

WFH has embraced vWD and other rare bleeding disorders in its strategic plan.

✂ *Women with Bleeding Disorders*

Many women with bleeding disorders lack proper diagnosis and care, especially in developing countries which experience particular social, economic and cultural barriers. Early diagnosis of women is critical to avoid unnecessary and invasive procedures such as hysterectomies and early treatment can prevent severe problems such as arthropathy.

✂ *Comprehensive care*

Over the years we have achieved a lot in the haemophilia community - safer and more accessible products, comprehensive care at specialist haemophilia centres. However, we should not be complacent and must take steps to ensure this continues.

🍴 Haemophilia and Ageing

Perhaps not something as young people we think much about, but we should. A great thing about haemophilia around the world now is that people can live to an older age – we need treatment and care that meets the needs of older people. We also need to look after ourselves, continue with recommended treatment and prevent joint damage.

🍴 Maintaining healthy joints

Staying fit and healthy is important for the future of our health – make sure you get good advice about how to recover from bleeds. Physiotherapy is a valuable part of the team of experts at our haemophilia centre – do you know your haemophilia physiotherapist?

GLOBAL FEAST

Haemophilia Foundation Australia will join other international Haemophilia Foundations including New Zealand, Ireland, United Kingdom, Portugal, Iran, Argentina and Netherlands for **GLOBAL FEAST** 2006.



You are invited to be an official **GLOBAL FEAST** host. Time your event around the month of September 2006. Invite your family, friends and work colleagues. Ask them to bring a donation instead of flowers, wine or a gift. Explain that the proceeds will go to HFA programs and services and to support people worldwide with bleeding disorders. Make sure you add that every dollar donated will make a difference to the lives of people struggling with lifelong and often disabling disorders.

If you are interested in participating in **GLOBAL FEAST** please contact us. We will send you everything you need to make your event a success; brochures, promotional items, posters and tax deductible receipts for your guests.

Why don't you organise a casual clothes day at school with a gold coin donation or a sausage sizzle?

HAEMOPHILIA AWARENESS WEEK

Haemophilia Awareness Week 2006 will be themed ***Busting the Myths*** and aims to dispel many myths about haemophilia.

You can participate in many ways during the Haemophilia Awareness Week -

- ❖ Host a "MYTHBUSTER" trivia night.
- ❖ Set up a stand in your workplace, school, hospital – busting the myths!
- ❖ Organise a fundraising event such as a casual clothes day, bike ride, walk, run or swim.
- ❖ Organise a theme day at your workplace or school – wear red and white and donate a gold coin.
- ❖ Host a luncheon, sausage sizzle or morning/afternoon tea.

HFA will provide you with promotional items for your event.



For more information about **GLOBAL FEAST** or **HAEMOPHILIA AWARENESS WEEK** please contact Natashia on 1800 807 173 or email ncoco@haemophilia.org.au or visit our website www.haemophilia.org.au.

Haemophilia Foundation Australia

Registered No.: A0012245M ABN: 89 443 537 189
1624 High Street, GLEN IRIS VIC 3146
Freecall: 1800 807 173 F: 03 9885 1800
E: hfaust@haemophilia.org.au
W: www.haemophilia.org.au

Editor: Natashia Coco

Contributors: HFA Youth Committee

HFA Youth Committee

Chair ~ Paul Bonner (SA)
Secretary ~ Sam Duffield (NSW)
Members ~ Anna Szynter (TAS), Chantel Roberts (VIC),
Craig Bardsley (QLD), Jodie Stephenson (QLD), Robert
McCabe (WA), Scott Christie (SA)
Executive Board Representative ~ Gavin Finkelstein (WA)
HFA Representative ~ Natashia Coco (VIC)