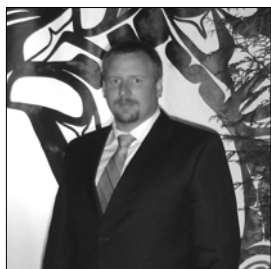


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**MESSAGE FROM THE CHAIR... Paul Bonner**

**HEMOPHILIA 2006 WORLD CONGRESS, VANCOUVER**



The Haemophilia 2006 World Congress was held in Vancouver, Canada from 21– 25 May.

After submitting my application to WFH I was lucky enough to be invited to attend the National Member Organisation (NMO) Training that was held prior to the Congress, as a youth delegate.

At the NMO training there were 110 people representing 80 different countries. Topics that were covered at the NMO training were Recruiting and Retaining Volunteers, Evaluating and Selecting Treatment Products, and Fundraising. We also had presentations on WFH's accomplishments and strategic plan, building and maintaining unified national haemophilia societies, as well as information for the WFH General Assembly.

These sessions proved to be very beneficial as the representatives from the different countries shared their problems and the ways in which they have overcome them, as well as offering advice to others who were having problems. The one thing that I did notice from talking to the different representatives was that all NMO's are facing the same issues, problems, and challenges. The only difference is that they are at different levels.

The NMO training was capped off with a banquet dinner, followed by music and dancing which carried on into the night. All who attended had a good time and enjoyed themselves.

The Congress commenced on Sunday evening with the opening ceremony. We were addressed by WFH President, Mark Skinner (USA), as well as being entertained by Police bag pipes and drum band and thunderous drumming and pow-wow dances by the Smokey Valley Drum Group of the Stolo Nation of British Columbia. This was followed by a welcome reception where everyone had the chance to catch up with friends both new and old, as well as make new ones. After the reception, Australian and New Zealand delegates had an Australasian get together.

The sessions that I attended at the congress were:

- ☆ *Prophylaxis* – this included Factor Prophylaxis: Unresolved Issues, Prophylaxis: when to Start, Management of Target Joints: Secondary Prophylaxis versus Early Synovectomy, Prophylaxis: When to Stop.
- ☆ *Psychosocial Issues Related to HIV/HCV Infection* – this included HIV/HCV – The Serbian Experience, Haemophilia in China: The Implications of Viral Infection, Viral Infection – Comparing Issues Across the Nations, Families: A Look at the Impact of HIV/HCV, Life History Project: HIV/HCV and Haemophilia.
- ☆ *Synovitis: What is the Best Treatment* – this included When is the Moment to Treat, Physiotherapy Treatment, Synoviorthesis with Efficina, Synoviorthesis with Rifampicin, Radioactive Synoviorthesis
- ☆ *Pain Management For Children And Adults* – this included Pain – the Fifth Element, Physiotherapy for Pain, Intervention in Response to Pain Survey, Haemophilic Pain in Children: Is a Pain Management Model Indicated?
- ☆ *Venous Access: Current Management* – this included an Overview of the Use of Implantable Venous Access Devices in the Management of Children with Inherited Bleeding Disorders, Venous Access – A

Family Perspective, The Use of Arterio-Venous Fistulas in the Management of Patients with Haemophilia, “Poking School, Cause Poking’s Cool”: A Self-Infusion Program for Children with Haemophilia.

- ★ *Issues for Carriers* –this included Ethical Dilemmas Associated with the Testing of Carriers, Reproductive Choices and Antenatal Diagnosis Available for Carriers of Haemophilia, Silent Sufferers, Social Issues for Carriers in Developing Countries: The Example of Jordan, Carrying: Issues for Women in the New Zealand Haemophilia Community
- ★ *Pain Management* – this included an Overview of Analgesics and Principles of Pain Management, Physiotherapy in the Management of Pain in Haemophilia, The Role of the Nurse in the Management of Pain in Haemophilia, Pain: A Patient’s Perspective.
- ★ *Cellular and Genetic Therapies* – this included Arosenius Lecture, Haemophilia Gene Transfer: Past Lessons and Current Obstacles, Clinical Gene Transfer Studies for Haemophilia B, Emerging Cellular and Genetic Approaches for the Treatment of Haemophilia.
- ★ *VWD – Clinical Management* – this included Clinical Management of vWD in 2006, Clinical Efficacy of DDAVP in Types 1 and 2 vWD, Von Willebrand Factor Concentrates: Indications for Use, Secondary Long-Term Prophylaxis in vWD.
- ★ *Musculoskeletal* – this included Hydrotherapy: Why and How? Deciding If, When and What Orthopaedic Surgery Will Help.

Some sessions that I attended were a bit past my level of knowledge, but were worth attending; however the other sessions were very relevant to my personal situation and provided me with some very useful information.

Along with attending the above sessions I was also asked if I would speak at a session on *Recruiting Young People into National Member Organisations*. The title of my presentation was *Youth Leadership and Mentoring Program: The Australian Experience*. In the presentation I spoke about how the Youth Committee was formed, vision, objectives and focus areas of the Youth Committee, as well as the make up of the committee and its responsibilities, things that we have accomplished, troubles we have faced, and future plans and directions of the program. Also presenting at the session was Dorte Lysgaard from Denmark on *What attracts Young People Into Voluntary Work?*, Siddhartha Ojha from India on *The Experience of Calcutta Youth Group*, and Christian Krough Madsen from Denmark on *Danish Youth with Haemophilia Meet In Cyberspace: Invitation to Join Los-Bleedos International*.

The session went very well with the entire panel being asked various questions, as well as receiving many positive comments and compliments. After the session I had a lot of people come and talk to me about different aspects of my presentation and asking for more information.

During breaks I was at the HFA exhibition booth. This was a great way to meet people, as well as answer questions that they had about HFA, the local foundations and the Youth Committee.

As part of the Congress registration we were treated to a trip to the Vancouver Aquarium in Stanley Park, Some of the animals that were there included Beluga whales, dolphins, seals, sea lions, and sea otters.

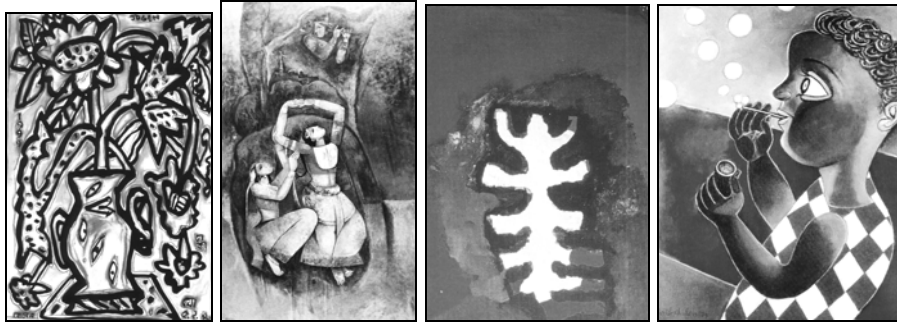
To cap the Congress off a farewell banquet was held on the Thursday night. This was a lovely night to say goodbye to the many friends that I made over the 7 days.

The following day I went to the General Assembly. This was very interesting. At the Assembly each country had a representative and decisions were made such as elected members of committees, and the 2010 Congress being voted, the winning country was Buenos Aries, Argentina. The next Congress in 2008 is in Istanbul, Turkey.

Overall the Congress was very interesting and rewarding and I was honoured to represent youth in Australia. For further information on any sessions contact HFA on 1800 807 173 or visit [www.wfh.org](http://www.wfh.org).

## THE EXPERIENCE OF CALCUTTA YOUTH GROUP

Siddhartha Ojha, Youth Member, Hemophilia Society Calcutta Chapter



The Calcutta Youth group started in 1995-96 with no concrete vision. But in 1999-2000, it started again to take a shape under the auspices of the *Danida project in India*. We got the patronage of the regional office in many ways. A renowned painter designed a logo, through a brain storming in group meeting.

The whole group was restructured. A Convenor and a Treasurer were elected. The group started raising funds, through selling greeting cards, coupons and musical evening. Eventually the group got due status in the Chapter's constitution through amendments. The elected Convenor was introduced in the Chapter Executive Council as an ex-officio member. Two of our members have been elected to the Executive Council, one of whom has become the Assistant Secretary.

By this time, we came to know that many of us were infected with HIV. In November 2005, with the support of the regional office we organised a three day special youth camp focused on awareness on HIV/AIDS, HBV and HCV with emphasis on sexual behaviour and marriage of the person with HIV, HBV and HCV. That was the first such camp in India. The Youth group received international acclaim and that stimulated us to work together to a focused area like:

- Creating awareness on haemophilia and blood borne diseases
- Networking with other self-help groups
- Increasing quality of life
- Capacity building
- Leadership skills
- Psychology counselling

The Youth group attended the Regional Camp organised by Hemophilia Federation (India) at Rabangla, Palling and Darjeeling at the altitude of between 6500-7500ft of Himalayan region. Scenic beauty of Himalaya gave us immense pleasure during our tour, and we forgot our pain of bleeding and depressed life of haemophilia. We also attended the state camp at Lava Lolegoan at a beautiful valley of Himalaya. The question can arise why we the youth prefer to arrange camps at Himalayan region? Because the attraction of Himalaya with his highest peak like Kanchanjanga, Everest, Annapurna, make us the realisation of our life and give us the feeling of broadness that help us to broaden our heart and mind. Youth group also arranged the local camp at Boakkhali at the sea beach of Bay of Bengal which was telecasted in a renowned TV Channel of Calcutta. The camp helps us to exchange our views and was full of joy and entertainment.

## DANISH YOUTH WITH HEMOPHILIA MEET IN CYBERSPACE

Christian Madsen, Youth Member, Danish Hemophilia Society

Invitation to join Los Bleedos International, Danish Hemophilia Society, Copenhagen, Denmark. International Member organisations often struggle to attract the interest and commitment of young members with traditional activities. In an attempt to rethink and revitalise youth work, the Danish Hemophilia Society launched Project Virtual Network, later renamed Los Bleedos, in 2003. The project embraces the internet as a new media to promote communication between young members. The project is run by a group of young volunteers supported by a project consultant. The volunteers have carried the project from the initial ideas through to the official launch of the web site [www.Los-Bleedos.net](http://www.Los-Bleedos.net) in October 2004, and continue to extend and improve the web site. In the first year since the launch, the number of registered users has risen to 75, compared to an estimated target audience of around 65

people. Los Bleedos has led to a 500% increase in activity over an existing web forum. As a spin-off from the main project, the surveys performed in the preparatory phase have shed new light on the interests and needs of Danish hemophilia youth. We believe the results to date show that Los Bleedos does have its place in the lives of young Danish hemophiliacs. We also believe that a similar need exists for young people from other countries. Therefore, the world congress in Vancouver will be the kick-off for Los Bleedos International, the international version of Los Bleedos. We invite youth from around the world to join in the network. Our vision is that the web site will foster greater cooperation between international youth groups.

**www.Los-Bleedos.net**  
is an online community for young people with bleeding disorders.

On [www.los-bleedos.net](http://www.los-bleedos.net) you can discuss all issues related to having haemophilia, von Willebrand disease or another bleeding disorder.

The Danish Haemophilia Society  
developed [www.los-bleedos.net](http://www.los-bleedos.net) in 2006

*Topics like:*

- Being young and having a bleeding disorder
- Conditions in different countries
- Sports – limits and opportunities
- Telling a girlfriend/boyfriend about the bleeding disorder

*Just:*

- Visit [www.los-bleedos.net](http://www.los-bleedos.net)
- Create a profile – it's free and you can be anonymous
- Read and write as much as you like

● ● ● ● ● We are different – and yet alike  
Let's meet on the Internet

*An invitation has been extended to all young people in Australia to join Los Bleedos – you too can meet people internationally and share your thoughts and experiences.*

## **YOUTH TRAINING WEEKEND, LAUNCESTON TASMANIA 12-15 OCTOBER 2006**

All young people with a bleeding disorder and family members are invited to attend the youth training weekend. The weekend will take place in Tasmania and over 3 days you will participate in leadership training, workshops such as discrimination issues, women's issues, managing your own health and lifestyle and holistic areas. There is an element of fun to the weekend as well with Sunday outdoor activities.

The Youth Committee has been planning the weekend and boys and girls from around Australia, aged between 14 and 30 years are invited to attend. For attendees under 18 years, an age appropriate program will be organised.

The Haemophilia Foundation Tasmania family camp will also be held the same weekend, at the same venue. If your family is attending the weekend, find out more about participating in the youth weekend.

For a full program and more information contact Natasha on 03 9885 7800 or [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au).

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McCabe (WA), Scott Christie (SA)*

*Executive Board Representative ~ Gavin Finkelstein (WA)*

*HFA Representative ~ Natasha Coco (VIC)*