



March 2010

NEWSLETTER

President's Update

The Haemophilia Foundation ACT (HFACT) is supported by the ACT Government through a service agreement which enables us to employ a counsellor to serve the needs of persons with haemophilia and their families. This funding was initially provided during the difficult times of blood-borne virus contamination of treatment products. While the quality of treatment products has improved considerably since those days, the legacy of those times has not gone away.

Our services are provided within the context of various strategies that the ACT Government also supports. These are:

- Public Health Outcomes Funding Agreement
- National HIV/AIDS Strategy
- National Hepatitis C Strategy
- ACT Health Action Plan
- Canberra Social Plan

The service agreement also fits with the objectives of our own HFACT Strategic Plan.

The main service which will be provided by HFACT under this agreement is to assist in the medical management of people with haemophilia and associated bleeding disorders and in minimising the personal and social impacts on such people, their partners, families and friends with special focus on:

- HIV/AIDS, hepatitis C and other related communicable diseases;
- Complications associated with haemophilia;

through the provision of a dedicated counselling and support service.

The service agreement provides for 12 hours per week which may be increased from time to time as needs arise. We provide ACT Health with regular reports on our activities and finances.

Our current service agreement is due to expire in June so Tim Crowden (Vice-president) and I have commenced negotiations with staff from the ACT Health to develop a new three-year

agreement. The discussions are going well and we expect the service agreement to be renewed.

There are ongoing support issues that the group still need to handle and the counsellor is there to help. Make sure that you avail yourself of the services of the counsellor when issues arise (see contact details elsewhere in this newsletter), no matter how small or large those issues are.

You will read elsewhere in this newsletter of the meeting of our women's group - Women's Wisdom. If you have not been to one of these meetings then I encourage you to consider attending. These grass-roots connections provide a friendly atmosphere where you can meet others who have had similar experiences. You never know what you may learn!

Fred Wensing

OUR MISSION

"To improve the wellbeing of the haemophilia community through mutual support, networking, advocacy and striving for optimal health care."

Multiple Engagements

You will have read in our last newsletter that Chris Wensing has become engaged to Laura Disbrey of Canberra. The Wensing family are also pleased to announce the engagement of Monica to Gilberto Arenas of Brazil. Monica and Gilberto met in Melbourne in 2008 when he was on holidays. They will be getting married in Brazil later this year. We would like to wish them all well for the future.



Monica and Chris with their prospective partners together at the National Zoo in January.

Medicare Chronic Disease Dental Scheme

I've recently become aware of the Medicare Chronic Disease Dental Scheme, which may well be of considerable interest to members.

In essence it is a scheme which provides up to \$4,250 of dental treatment over a 2 year period. After 2 years you can be referred for a further 2 years.

To be eligible you must have a chronic medical condition (which haemophilia is) and be receiving care under a 'GP management plan',

which typically involves 2 other health care providers. Your oral health must be impacting, or likely to impact, your general health. Your GP simply needs to complete the management plan paperwork and refer you to a dentist.

The scheme appears to cover the majority of treatment that improves your 'oral health or function'. You may have to make some contribution to the cost, depending whether your dentist bulk bills or charges their own fees.

Full details are available at <http://www.health.gov.au/internet/main/publishing.nsf/Content/Dental+Care+Services>

If you think you might be eligible give your GP a call.

Phil

Medical I.D. Wristbands

Xavier started primary school this year. Along with all the 'regular' items that adorned our shopping list ('cool' lunch box, 'cool' drink bottle, school uniform, sports uniform, school bag and library bag - the list seemed endless), we also had to consider a new medical identity bracelet. The last one was well and truly lost - even our expeditions into the bottom of the toy box were exercises in futility (but we found a whole lot of other items that we thought were gone forever). Of course, it had to be 'cool'.

Searches on the Internet provided many options. And an enormous price range in many different currencies. But the big surprise was the infomercials, the video testimonies from satisfied customers and - wait for it - a live chat room where you can ask questions before you buy! And don't forget all the videos on YouTube.

We, or rather Xavier, settled on the Medical I.D Wristband made by A.J. Hart group in Canada.

There were lots of options for suppliers in Australia and overseas so we could choose the right wristband at the right price. It is hard wearing and comfortable. The ID card is kept securely and discreetly inside the bracelet, in the 'secret place' as Xavier says. The bracelet is 100% waterproof and is OK to use in the pool (tried and tested!). Xavier likes it and, best of all, so do all the teachers. The first trip to the first aid room was a success. Not only was it a very minor injury but mum and dad also received the telephone call to confirm that the first aider was doing the right thing.

Medical I.D. Wristbands:

- Fit wrists with a circumference of 5-6"
- Come in seven colours to choose from: blue, pink, pink,-camo, green-camo, orange, charcoal and purple with flowers.

- Include two ID cards with



each bracelet.



World Federation Congress

The World Federation of Haemophilia has an international congress of scientific and medical experts every two years. The congress provides a forum to discuss global issues in Haemophilia care as well as providing an opportunity to exchange experiences at the grass roots level.

The HFACT has been fortunate to have local representation at the last three congresses. We are pleased to find out that Maria Wensing has been invited to join the HFA delegation to the next congress being held in Buenos Aires, Argentina in July this year. She will be a good ambassador for Canberra and Australia and be able to share

her experiences of our small group, especially among other Spanish-speaking delegates.

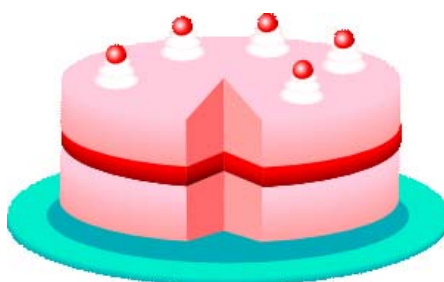
Go to the following website for more information:

www.hemophilia2010.org

Women's Wisdom

On Sunday afternoon 21 February, the ladies associated with HFACT met for a social gathering for afternoon tea to share laughter, recipes, insights as well as words of wisdom. This time around we especially invited Sharon the Haemophilia Clinic nurse and Phil the counsellor to introduce themselves and give us a little background, personal history and a run down on their life so far in the world of haemophilia. There were 11 of us altogether and included one new arrival who hadn't previously attended this

social event before. It's always great to meet new people even if they prefer to keep their contact with the group to a minimum. The feedback is always positive. All are given the opportunity to share their stories and we often pick up such useful information from each other that just doesn't



seem to be readily available through other avenues. Of course most of the afternoon consists of laughing, joking and eating but there are always the serious issues to deal with as well. Please consider joining us at our next event, on the 19th of June, if you are a member of the group or associated with anyone in anyway with the group and, of course, if you are female!. We welcome new faces and there's always room for more!

Lorraine

Haemophilia Contact Numbers

Canberra Hospital

Switchboard: 6244 2222
Haemophilia Treatment Centre: 6244 2286
(Thursdays)
Oncology Treatment Room: 6244 2424
Oncology Reception: 6244 2188
Physiotherapy: 6244 2154

Haemophilia Foundation ACT

President: 6291 7920
or 0409 831 844
Counsellor: 0409 830 472

Haemophilia Foundation Australia

Office: (03) 9885 7800
or 1800 807 173

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