

In this Issue...

- ☆ Introduction from Anna
- ☆ History of Treatments
- ☆ Greetings from the Committee
- ☆ Role Model
- Something for the Kids**
- ☆ Red and white day fundraising
- ☆ Word Find
- ☆ History of the Easter Bunny

INTRODUCTION FROM ANNA...

My name is Anna Sznyter. My face would be familiar to some of you who attended the 2nd Australasian Haemophilia Conference in Queensland during October 2003. I was approached by HFA and offered



the position of Chairperson for the Youth Committee, which I accepted. I'd like to take a few moments to introduce myself to you all. I am a 21-year old student in Hobart, Tasmania. At the moment I am in the process of completing my final year in a science degree at the University of Tasmania. My majors are in Psychology and Biochemistry. In my spare time I enjoy spending time with friends: going to movies and video nights, shopping, meeting for coffee or a meal, or simply spending time together. On the odd occasion I

get adventurous enough to travel, go camping, bushwalking, or whatever other outdoor adventure takes my fancy. I have a passion for spending time with young people, and have many experiences as a youth leader at holiday camps in Tasmania. So for me, chairing the Youth Committee is another exciting new role to undertake.

Haemophilia is one of the important aspects of my life. 'Haemophilia' is a word that goes back to my earliest memories. My younger brother was diagnosed as suffering from haemophilia A as a toddler, and I was diagnosed as a carrier while still in primary school. The condition has been a part of my life since that time. Through the years I have watched and experienced the various influences blood clotting disorders have on the lives of people living with them, as well as on the issues it raises for the family and friends of the affected person.

One of the biggest revelations I had at the recent Queensland conference was how far medical treatments have come for people living with haemophilia today, and the resulting opportunities it brings to people living with blood disorders. I had reinforced to me many times throughout the four days that haemophilia doesn't stop you from doing things as long as you know your limits. That's the message I want to bring and build on. To keep it that way, we need to look to the future. That's where you can all play a role. To make this new committee work we need people to get involved as members of the committee, and people to share their ideas for what they would like to see the Youth Committee accomplish. What are the issues that interest you, what areas do you think there needs to be more information available on? I also want to encourage you to all think about the various ways you can accomplish awareness about blood clotting disorders within your friends, schools, and local communities. Your involvement is vital to make this work. So let's work together.

I look forward to exciting things in the future, and to sharing the Youth Committees progress with you all. Please feel free to email me at hfaust@haemophilia.org.au or contact HFA for more information on 1800 807 173.

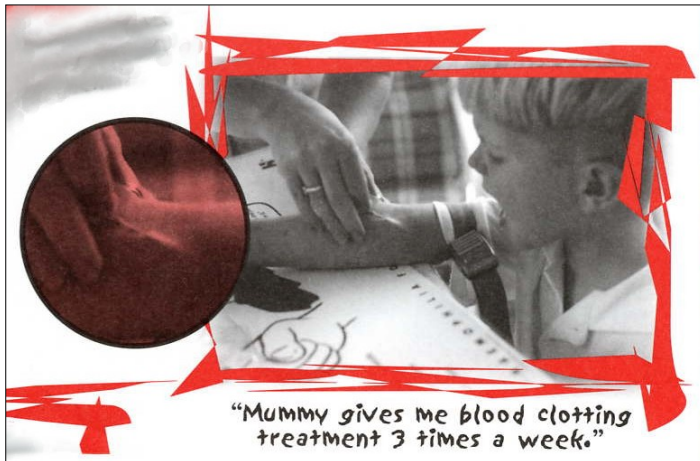
Anna Sznyter

HISTORY OF TREATMENTS...

(The following are excerpts from World Federation of Hemophilia website, written by Dr Paul Giangrande, WFH Vice-President Medical)

Early treatments

Many reputable scientists claimed early success in treating with unusual substances. A report in *The Lancet* in 1936 extolled the virtues of a bromide extract of egg white. As recently as 1966, a report in the esteemed scientific journal *Nature* claimed that peanut flour was also effective for the treatment of haemophilia. The first hint of success came with the report from R.G. Macfarlane in 1934 that snake venoms could accelerate the clotting of haemophilic blood, and he reported success in controlling superficial bleeds in people with haemophilia after topical application.



Blood transfusion

However, the major advances came from developments in the field of blood transfusion. A report from a surgeon, Samuel Lane, in *The Lancet* in 1840 described the control of post-

operative bleeding with fresh blood in a boy with severe haemophilia. However, a lack of understanding of blood groups and basic transfusion methods hindered further development at the time. The identification of factor VIII and the development of specific assays then permitted the subsequent development of therapeutic materials.

Plasma concentrates

In the early 1950s, plasma from animals was used for treatment. While often effective, allergic reactions to these porcine and bovine materials were frequent and often severe. The work of Dr. Edwin Cohn in developing fractionation of plasma with variation of temperature and concentrations of saline and alcohol led to the development of fairly crude plasma concentrates of human factor VIII in a number of centres ("AHG" or "antihaemophilic globulin").

A truly major advance was the discovery by Dr. Judith Pool in 1965 that slow thawing of plasma to around 4°C led to the appearance of a brown sediment which was rich in factor VIII, which she called cryoprecipitate. Within a decade, lyophilised coagulation factor concentrates made an appearance. These offered considerable advantages: they could be stored in a domestic refrigerator at 4°C, and permitted the administration of a large and assayed quantity of coagulation factor rapidly and in a small volume. The availability of such products facilitated home treatment, allowing patients for the first time to treat themselves at home, work, school, or even whilst on holiday abroad - freeing them from the physical and psychological shackles of haemophilia.

However, we now recognise that this introduced the potential for the transmission of viruses. The impact of HIV was particularly devastating, with large numbers of patients around the world being infected in the period 1979-1985. The hepatitis C virus (HCV) was first identified in 1989, and it soon became clear that an even higher proportion of people with haemophilia had been exposed to this virus which results in chronic liver disease. Fortunately, the introduction of physical treatments of concentrates such as exposure to heat or the addition of a solvent-detergent mixture has effectively eliminated the risk of the transmission of these viruses. Another landmark was the recognition by Prof. Pier Mannucci in 1977 that desmopressin (DDAVP) could boost levels of both factor VIII and von Willebrand factor, and this remains a useful option in mild forms of these conditions.

Recombinant products and gene therapy

The structure of the factor VIII gene was characterised and cloned in 1984. This led to the availability of recombinant (genetically engineered) factor VIII a decade later. The availability of safe products has stimulated the growth of prophylactic treatment, although it must be emphasised that the concept is certainly not new and was developed by Prof. Inga Marie Nilsson in Sweden in the 1950s. The rate of progress continues apace, and gene therapy is a realistic goal. However, we do not forget that many people with haemophilia around the world still receive absolutely no treatment. Perhaps the current position can best be expressed in words paraphrased from Sir Winston Churchill: this is not the end of our struggle to conquer haemophilia, and not even the beginning of the end. However, we can at least say that this is the end of the beginning of our campaign.

GREETINGS FROM COMMITTEE... Keep an eye for next issue for more committee members.



Robert
McCabe
(WA)



Rebecca
Head
(SA)



Chantel
Roberts
(VIC)

ROLE MODEL ~ PATRICK MICHAEL RAFTER



Born: Mt. Isa, Queensland

Resides: Australia

Birthday: 28th December 1972

Mission: "If I can help one child, it's worth everything to me"

Interests: Golf, Music, Snow Boarding, Fishing, Boating, Surfing, Beaches, He Loves supporting and watching other Aussie Teams sports.

Teams: Brisbane Broncos, Brisbane Lions, and Bank of Queensland Reds
Pat was awarded 2002 Australian Of The Year.

Sporting Career

• 1991 Turned Professional

• Two time US Open Grand Slam Winner, 1997 & 1998

• Australian open Doubles Title (with Jonas Bjorkman), 1999

• 10 Singles Titles & 10 Doubles Titles

• No. 1 player in the world, 1999

• Finalist of Wimbledon 2000 and 2001

• Semifinalist of Australian Open 2001

• Selected Olympian

• 10 Singles Titles and 10 Doubles Titles

(Extracted from www.cherishthechildren.com.au)

HAEMOPHILIA AWARENESS WEEK...

World Haemophilia Day is celebrated on April 17th by haemophilia organisations around the world, and provides a unique opportunity to raise public awareness of haemophilia, von Willebrand disorder and bring attention to the tremendous needs of the community. The 2004 awareness campaign is titled, "How Aware Are You?" and aims to educate the public about haemophilia and von Willebrand disorder. WFH theme is "Visit your treatment centre regularly". What can you do?

☆ Organise a casual clothes day at school or work and participants donated a gold coin

☆ Put up a display in your workplace, school, local library

☆ Hold an Easter egg hunt as Haemophilia Awareness Week falls during the Easter period.

For more information or and resources e.g. posters and balloons please call Natasha on 1800 807 173.

Something for the kids...

RED AND WHITE DAY FUNDRAISING



When 12 year old Lauren Albert finishes school, she aspires to become a research scientist so she can find a cure for haemophilia. "My brother Sam has severe haemophilia, so I want to do everything I can to help find a cure," Lauren said.

Lauren decided to hold a 'Dress Red and White Day' at her school, Saint John Vianney's Catholic Primary to raise funds for the haemophilia. The red and white theme was referring to the red and white blood cells. All children who participated were asked to make a gold coin donation.

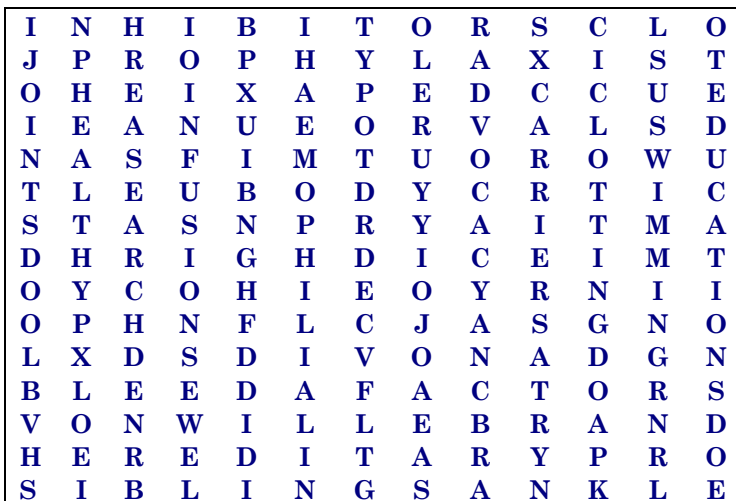
The 'Dress Red and White Day' raised nearly \$400 towards haemophilia services. Lauren spoke to the students at assembly about haemophilia and books were read to the lower grades to help them understand what haemophilia is.

Lauren said she is really proud how the whole school got involved. "I found it enjoyable to know that by doing this I could be helping make some one with haemophilia's life a lot easier."

Lauren won the HFA Matthew Schneider Youth Award 2003 for her fantastic efforts.

WORD SEARCH

Below are 18 used to describe bleeding disorders, find them hidden in the word search puzzle.



ADVOCACY

ANKLE

BLEED

BLOOD

BODY

CARRIERS

CLOTTING

EDUCATION

FACTORS

HAEMOPHILIA

HEALTHY

HEREDITARY

INFUSIONS

INHIBITORS

JOINTS

PROPHYLAXIS

RESEARCH

SIBLINGS

SWIMMING

VON WILLEBRAND

HISTORY OF THE EASTER BUNNY

Opposite to common belief, the Easter Bunny is not purely a product of commercialization. Although the rabbit is a major advertising symbol during Easter, it symbolized springtime long before Christian times. Pagans celebrated the festival of Eastre, a goddess of the dawn, springtime, and babies. Her symbol was a rabbit. The Christian context of the Easter Rabbit originated in Germany, where a visit by the Easter Bunny was "childhood's greatest pleasure." Children believed that the Easter Bunny left them a nest of colored eggs if they were good. Boys made egg nests out of their caps, and girls used their bonnets. This custom is today celebrated by using baskets to hold eggs left by the Easter Bunny.

