



HAEMOPHILIA FOUNDATION AUSTRALIA  
... CELEBRATING 25 YEARS AUTUMN 2004

## Fantastic fundraisers...

### HAIRCUT RAISES \$3,000 FOR HAEMOPHILIA

**B**radley Duke, Rockhampton City Council's deputy CEO, has a history of haemophilia in his family. His father-in-law and his brothers all have this rare and extraordinary disease.

When Bradley and his wife Marie were expecting a baby, they knew there would be a chance that if they had a boy, he too would have haemophilia. "This would never have stopped us from having children," Bradley said.

When Bradley's son Brendan was born, he was diagnosed with haemophilia. Bradley wanted to provide Haemophilia Foundation Queensland (HFQ) with some monetary assistance, as he knew how difficult fundraising can be, especially considering that other diseases are more common and have a much higher profile in the community.

"I thought, well my son Brendan has haemophilia, so why not help HFQ out," Bradley said. After growing his hair to attend a Rolling Stones concert with Marea, Bradley finally decided to shave it all off for a cause.

Bradley's efforts raised more than \$3,000 for HFQ and now five year old Brendan wants a haircut just like Dad.



*Bradley before the haircut with his kids, Brendan and Madeline.*

Bradley believes that haemophilia is still largely misunderstood. His suggestion is that more people partaking in fundraising, especially high profile people and those that have been impacted by haemophilia will help to raise awareness and funds for further research.

Bradley said that the biggest misconception about haemophilia is the belief that sufferers can bleed to death with a minor wound or abrasion. "People have so little or no knowledge of the seriousness of bleeding joints," Bradley said.

## RED AND WHITE DAY

**W**hen 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 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 received the HFA Matthew Schneider Youth Award 2003 for her fantastic efforts.

*Pictured right: Lauren with her award*



## SCHOOL DANCE

Callaghan College Waratah Technology Campus held a dance on 28th October 2003 to raise funds for haemophilia research. The dance was organised by the Student Representative Council and 16 year old Brendon Bulleen who has haemophilia. The dance was a huge success raising \$1,000 in total with \$400 being sent to Haemophilia Foundation Australia.

Brendon said it was a challenge organising the fundraiser but he also enjoyed it at the same time.

If Brendon could change anything that night it would have been if he could have seen it all happen, "Because of a bleed in my foot I could not attend the dance," Brendon said.

## MARATHON RUN

Suzanne Pelz ran her personal best time of 1hr45min in a half marathon in Melbourne on 12th October 2003, raising over \$700 for Haemophilia Foundation Australia.

Her motivation was her 1 year old nephew Tyrone who has haemophilia. This year she is going to run a full marathon and her motto is "Double the distance, double the money"



Message from the Development Manager...

HAPPY NEW YEAR!

This year is a very special year – Haemophilia Foundation Australia is celebrating 25 years! In the past 25 years there have been significant changes.

In the newsletter you will read about our advocacy campaign for the best treatment products in Australia. Please support the campaign!

A major highlight has been our website re-development in October last year. The site has many features and information and is updated frequently. Visit us at www.haemophilia.org.au and don't forget to sign up for our email newsletters.

Thank you to those who supported our Spring and Christmas appeals. For this special year let's aim to raise \$100,000 for programs and services such as the Youth Mentoring and Leadership Program, camps, research and education!

I hope you enjoy this autumn edition.

Regards,

Handwritten signature of Natasha Coco.

Natashia Coco

# Haemophilia Awareness Week 11th – 17th April 2004

## HOW AWARE ARE YOU?

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.

This years awareness campaign titled, "How Aware Are You?" aims to educate the public about haemophilia and von Willebrand disorder. Events and promotions will be organised across the States/Territories. Should you want to become involved please call us on 03 9885 7800.

## HOW AWARE ARE YOU?

- Without proper treatment **haemophilia** can be life threatening.
- There are 1,800 people in Australia who have **haemophilia**.
- There are two types of **haemophilia** –
  - \***Haemophilia A** – Classic – is cause by a deficiency of blood clotting factor VIII.
  - \***Haemophilia B** – Christmas disease – is cause by deficiency of blood clotting factor IX.
- **Haemophilia** is hereditary, but in 1/3 of cases, **haemophilia** appears in families with no previous history.
- **Haemophilia** symptoms can include spontaneous bleeding, bleeding into joints and associated pain and swelling, and bruises.
- **Haemophilia** affects males almost exclusively, and is passed on through unaffected females who carry the defective gene.
- There are a range of treatments available for **haemophilia** and **von Willebrand disorder** and they are given intravenously.
- **von Willebrand disorder** affects approximately 1% of people in Australia.
- Many people with **von Willebrand disorder** experience mild or few symptoms, whilst others may experience bleeding such as frequent nosebleeds, easy bruising, heavy menstrual flow or excessive bleeding in the mouth.
- **von Willebrand disorder** affects both males and females.
- **von Willebrand disorder** is an hereditary bleeding disorder.
- There is no cure for **haemophilia** or for **von Willebrand disorder**.
- **von Willebrand disorder** is due to a deficiency of von Willebrand factor.

## What does Haemophilia Foundation Australia (HFA) do?

HFA works for and represents all people with haemophilia and related bleeding disorders and their families through **advocacy, education** and promotion of **research**. HFA supports a network of State/Territory Foundations.

HFA is a National Member Organisation of the World Federation of Hemophilia.

For more information on any of these projects or if you can assist please call Natasha on 03 9885 7800.

### Can you help...

We are currently seeking funding for the following projects:

- Youth Leadership and Mentoring Program.
- Research.
- Haemophilia Foundation Victoria Family Camp in April 2004.
- Haemophilia Foundation New South Wales Family Camp in November 2004.
- We are also seeking a donation of a new digital camera for HFA to reduce our production costs for newsletters and publications.

## YES, I want to support Haemophilia Foundation Australia...

Name: _____ Address: _____ _____ Phone: _____ Email: _____	Please find enclosed my donation of: <input type="checkbox"/> \$150 <input type="checkbox"/> \$50 <input type="checkbox"/> \$100 <input type="checkbox"/> \$75 <input type="checkbox"/> \$300   Other: \$ _____ Please find my cheque enclosed made payable to Haemophilia Foundation Australia <b>OR</b> please debit my: <input type="checkbox"/> Bankcard <input type="checkbox"/> MasterCard <input type="checkbox"/> VISA <input type="checkbox"/> Amex <input type="checkbox"/> Diners _____ Cardholder's Name _____ Expiry Date: ____/____/____ Signature: _____ HFA respects your privacy. You may request to be removed from our mailing list by contacting us at any time. <input type="checkbox"/> Do not publish my name
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Gifts over \$2 are tax deductible

Please return this coupon together with your donation to HFA, 1624 High Street Glen Iris Victoria 3146

## WHY IS THE HAEMOPHILIA COMMUNITY SO FRUSTRATED?

Individual members and their families and friends joined HFA recently to campaign for the safest haemophilia treatment products for everyone in Australia. The haemophilia community has been devastated over the years by blood borne viruses which came through the blood supply before treatments were effective to remove them. No matter how safe blood screening and treatment processes are, there is an ongoing fear that known or new viruses may slip through. Most people want to use alternatives to blood products for their treatment. HFA has argued to governments on their behalf that safer alternative products should be provided when these are available to prevent the catastrophes of the past. The community is frustrated however, because the delay over several years has resulted in government policy which is out of step with other countries.

Members embraced our "Postcard Campaign" by sending postcards to their local State/Territory and Federal Members of Parliament and to key MP's to draw attention to the plight of people who are dependent upon these treatment products.

It is not too late for H.Link readers to join this campaign. If you want to know more you can download information and postcards from our website [www.haemophilia.org.au](http://www.haemophilia.org.au) or phone 1800 807 173 for an update on our progress.

This is the most significant issue facing the haemophilia community currently and we believe you too can help us to make a difference.

The realities:

- People with haemophilia have always been amongst the **first to be exposed** when an infectious agent enters the blood supply.
- Federal/ State/ Territory governments have **failed to make a policy decision** to enable people to switch from plasma derived treatments to safer recombinant treatments.
- Some MP's have told us they support the required policy change and that implementation plans are in place but they **have not made the decisions** to ensure it happens.

- We have worked with all governments in **good faith**, but the necessary decisions have not been made, and some have even been deferred to further committees.
- In the meantime most people with haemophilia still must use plasma derived treatment products and worry about the **risks of known viruses**, agents such as vCJD (Mad Cow Disease) and as yet unknown viruses which may infect the blood supply.
- **No treatments are 100% safe**, but we can and should reduce some of the risks.
- Governments do not have to put the health of people with haemophilia at risk when **alternative, safer** treatment products are available.

### A PLEA TO ALL MEMBERS OF PARLIAMENT

- the haemophilia community in Australia has been **devastated by blood borne viruses** in the past
- **discriminatory government policy** means that most people must still use clotting factor treatments made from human blood plasma
- there remains a risk of **blood borne viruses** slipping through the blood supply
- there is a **critical shortage** of plasma derived factor VIII
- **safer, man made recombinant treatment products** carry **less risk**
- **alternative recombinant clotting factors** can be supplied if governments agree
- **Australia has slipped below** international best practice standards
- adoption of the recommendations in the government report to switch people to recombinant treatment products by 2004 was again **deferred by all health ministers** in November. This report has now been **delayed for 3 years**
- even with the new National Blood Authority and the agreement of all jurisdictions for blood sector reform, treatment for people with haemophilia **still does not meet the benchmark**

**WILL PEOPLE WITH HAEMOPHILIA HAVE TO WAIT FOR ANOTHER DISASTER BEFORE THEY ARE HEARD?**

Contact Haemophilia Foundation Australia 1800 807 173 [www.haemophilia.org.au](http://www.haemophilia.org.au)



## Come along to a BE-TSAR night....

In May 2004, Sydney will welcome guests to the **Be-Tsar Cocktail Party** – haunting Russian melodies skillfully played by the violinist, Bloody Mary's, borsch shots, and a tasty selection from the blini bar!



The **Be-Tsar Cocktail Party** follows on from the successful launch in 2003, which raised over \$80,000. All monies raised are directed towards the Youth Mentoring and Leadership program.

Australia's leading artists have united in support of this Be-Tsar evening and have donated recently completed works to be auctioned on the night. It will represent a range of artists including Rex Dupain, Maclean Edwards and Rob Ryan. There will also be Babushka dolls for sale and a lucky door prize.

Ticket prices are \$75 per head and include finger food and alcoholic beverages. Sponsorship and corporate packages are available.

For further information or an invitation please call Haemophilia Foundation Australia on **1800 807 173**.

Haemophilia Foundation Australia gratefully acknowledges the outstanding generosity of the contributing artists, Serena Sanderson Catering, Sotheby's and the Volunteer Committee.



**Haemophilia Foundation Australia**

Registered No. A0012245M ABN 89 443 537 189

**1800 807 173**

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- Web: [www.haemophilia.org.au](http://www.haemophilia.org.au)

## Haemophilia Foundation Australia thanks you

Haemophilia Foundation Australia would like to acknowledge contributions  
between 1st July 2003 and 31st December 2003 from our supporters.

Please accept our apologies for omissions.

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