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HAEMOPHILIA FOUNDATION AUSTRALIA

www.haemophilia.org.au

MESSAGE FROM THE COMMITTEE

We would like to say a big hello to you all in 2005. We know we are just about half way through the year, but this has been the first opportunity we have had.

The committee re-joined in February and has been meeting regularly. One of the big projects is the 13th National Haemophilia Conference youth stream which will be held in Melbourne in September this year. There is more information in this newsletter. We hope you will be able to join us.

If you have any feedback or comments for the committee please contact us on hfaust@haemophilia.org.au. Hope you enjoy this edition.

Youth Committee



13th National
Haemophilia
Conference
Friday 30 September – Sunday 2 October 2005
Melbourne



HAEMOPHILIA FOUNDATION AUSTRALIA
Integrating Knowledge and Practice

National conferences are an opportunity for the community to get together and share information. In 2003, the national conference was held in Queensland and for the first time there was a youth stream. The youth stream had a separate program, and this included going to Seaworld, Parasailing and workshops.

"We talked about all sorts of things about the haemophilia and how to deal with everyday issues. This was so interesting as other people worry about the same things I do and speaking to the older kids helped me, I am not so worried anymore. It was good to talk to someone who understands and can relate to your story!"

"I attended the sibling session. Our group was mainly girls and we talked about issues for siblings and worked on resource material. As we got talking it was easy to see that when we were younger we were unsure how to deal with our emotions and the way we were feeling and acting. We felt guilty when we got jealous and sometimes got angry and didn't know how to cope."

Feedback from the youth delegates from the Queensland Conference 2003

An exciting program of activities has been organised by the HFA Youth Committee for the 13th National Haemophilia Conference. You can meet new friends, see old ones, have fun and learn at the same time.

Friday - concurrent youth stream at Rydges as part of the conference program

Saturday - adventure activities off site

Sunday - workshop and wrap up session at Rydges

There is more information and a registration brochure in *National Haemophilia* or alternatively you can download details from our website www.haemophilia.org.au/conferences or call 1800 807 173 and we will post it out. See the HFA website for program updates. Your local Foundation may help with funding.

C'mon, join the 2005 Youth Conference – you will get a lot out of it!

A STOPOVER IN THAILAND

BY ANNA SZNYTER



During November of 2004 I took an opportunity to travel. One of the highlights of my trip was a three day stopover in Bangkok, Thailand. My initial impression of the city created while driving in a taxi from the airport to my hotel was that the weather, although beautifully sunny and warm, was extremely humid. One thing I quickly learned was that the Thai people are very friendly and approachable, leading to the saying 'Thailand: land of a thousand smiles'. I spent the afternoon of my first day shopping in a 6 storey shopping complex, stopping for a short dinner break at one of the inexpensive, but delicious traditional food stores. There were so many stores to browse, selling everything including mobile phone

accessories, clothes, jewellery, furniture, gift ware, and electrical goods. Up bright and early on the second morning to start a day trip to an Orchid Farm, Snake Zoo, Floating Markets, and Rose Gardens. We fitted in a short stop for lunch at the Bangkok Zoo, listening to the sounds of the animals while we ate. A special event in my day was patting a baby elephant and enjoying an elephant ride while at the Rose Gardens. Here, we also were treated to a traditional Thai cultural show, with highlights from many aspects of the Thai culture and filled with many smiling faces and bright colours. I even patted a cobra snake while visiting the Snake Zoo, yuck! The Floating Markets were a fantastic place to explore, with many items for sale, but the best part was seeing colourful and unusual fruits that I had never seen in Australia before. On my final day, I spent the morning visiting the Royal Palace and Temple of the Emerald Buddha. It was interesting to explore the religious objects important to the majority of Thai people. Overall, Thailand is a fascinating place to explore, with many interesting and colourful sights.

PUNCTURES AND PICTURES –

Decisions about Body Piercing and Tattooing for People with Bleeding Disorders

(This is a reprint from article in National Haemophilia written by Maureen Spilsbury, counsellor and Beryl Zeissink, haemophilia nurse who both work at the Queensland Haemophilia Centre in Brisbane.)

WHAT IS BODY ART?

- Tattoos are permanent designs on the skin made when coloured ink is injected under the skin.
- Body piercings are permanent holes made in the skin with a sharp instrument, usually a stud gun or needle.

There are many reasons why people choose to have body art and there are also many different body art studios to choose from. It is important that you think carefully as you choose your body art so that you can be happy with the permanent result and that you do not cause harm to yourself in the short or long term.

WHY YOU NEED TO TALK TO YOUR HAEMOPHILIA CENTRE FIRST

People of all ages who have inherited bleeding disorders such as haemophilia or von Willebrand disorder need to consider the issue of bleeding after getting a “puncture or a picture”. Bleeding even from a small wound may cause unnecessary bleeding which can lead to infection and scarring.

Each Haemophilia Centre will have policies about the use of treatment products for getting body art done, so it is important to talk to the staff at your Centre about the issue.

It is important not to get body art done without adequate attention to the issue of bleeding and simply “hope for the best”. It is imperative to contact your Centre immediately if you have any concerns about bleeding following body art.

QUESTIONS TO ASK YOUR CENTRE

- What do I need to consider in order to get a puncture or picture?
- Have you had people with inherited bleeding disorders who have had this procedure before? Have they had any problems?
- What treatment/extra treatment of my clotting product do I need to have before and after the work?

BLEEDING DISORDERS AND BODY ART

Whether you have mild, moderate or severe haemophilia A or B or von Willebrand disorder or another bleeding disorder, it is important that you consider the impact of both bleeding and infection after the process.

It is wise to always discuss your plans with your Centre well before you plan to have the body work done. This will allow you to understand all of the implications of the procedure and also to make plans to ensure that you do not have any problems.

It is inadvisable to have very vascular areas of your body pierced. Some body area piercing may cause life-threatening bleeding, eg tongue, genitals. Many areas for body piercings also have surprisingly long healing times, which increases the risk of bleeding and infection in the long term.

LEGISLATION

Some States and Territories are working towards approval for body artists by local governments. Check that the studio has appropriate infection control standards and techniques. Ask about local legislation requirements. Visit a number of studios before you make your decision. You may need to show proof that you are over 18.

PREPARATION

Make an informed decision. Talk to others and do not rush into getting body art done. Although jewellery can be removed your skin will never look the same, and removing tattoos is expensive and painful.

THINGS TO CONSIDER

- Any general sickness may slow healing.
- Start small and see how you manage.
- Consider a dye test for allergies and discuss allergies with your artist, as well as healing problems.
- Remember to consider the impact of the body art on work and social situations in the long term.
- Be aware that the use of inadequate infection control techniques during body art is seen as a risk factor in the transmission of blood borne viruses.

SAFETY

- Discuss with the artist early in the process that you have a bleeding disorder and also about skin diseases or blood borne viruses.
- Do not let friends or people who work outside of established body art premises do your body art.
- Shop around, ask others where they have had a good experience.
- Check that the body artists are members of their professional associations for their industry. If they are unwilling to discuss the issue, leave the shop.
- Make sure the artist has a clean, tidy, well lit studio and work bench. Enquire about the hand washing techniques they use throughout the procedure and also whether they use gloves.
- Make sure all equipment, needles, razors and inks are in sterile bags and that they are opened in the person's presence. If they use needles, ask how they are sterilised.
- Ask about follow-up reviews with the artist.

ALTERNATIVES

Some people might want to consider getting a henna tattoo for a special occasion. These tattoos are not permanent and are applied at cosmetic services. Before getting a henna tattoo you need to make sure that you do not have any allergies to the product which will be used. Henna is a dark red dye from the leaves of the henna plant.

A FINAL WORD

Getting a piece of body art done is often considered to be a simple procedure, but adults and children with bleeding disorders will need to take a little extra time to explore the process. Seek out a staff member at your local Haemophilia Treatment Centre with whom you feel comfortable to talk about it with, before making any concrete plans. A little time spent on thinking carefully at the start may save a lot of pain and distress later on.

SOMETHING FOR THE KIDS...

WHAT ARE BLEEDING DISORDERS?

Bleeding disorders is a description given to medical problems which result from poor blood clotting or continuous bleeding. This bleeding may cause bleeding into muscles, joints or organs which can cause long term damage and disability if untreated.

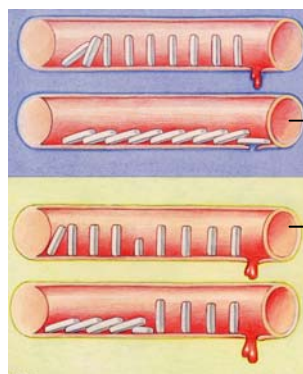
Bleeding disorders are usually caused by problems in the blood vessels or in the blood itself. Abnormalities can be in blood clotting factors or in platelets. The most common of these bleeding disorders are haemophilia and von Willebrand disorder. Neither is a disease that you can catch. People are born with it.

Haemophilia is a rare blood clotting disorder, in which there are low levels of one of the essential clotting factors. It is hereditary. It mainly affects males, and it is passed on through them and females who carry the defective gene. It occurs in approximately one in 10,000 males. However, a third of occurrences appear in families with no previous history. It then becomes hereditary.

Haemophilia A which is sometimes called classical haemophilia is the most common form and is due to deficiency of factor VIII. **Haemophilia B** (sometimes called Christmas Disease because it was named after Stephen Christmas, the first person diagnosed with haemophilia B) is due to deficiency of factor IX.

von Willebrand disorder is a combined deficiency of factor VIII and a platelet abnormality. It is also hereditary, but has a different genetic pattern, and it affects both males and females. There are different levels of severity of haemophilia (mild, moderate, severe) and von Willebrand disorder (type 1, 2, or 3).

The common belief that a person with a clotting disorder gushes blood from cuts and will bleed to death is a myth. The problem is that bleeding is for longer and treatment is often necessary to stop the bleed. Treatment is by injecting the missing clotting factor into a vein. People usually learn to do this themselves. Prophylaxis is treatment given to prevent a bleed occurring.



WHAT IS HAEMOPHILIA?

→ There are many blood clotting factors in the blood. The clotting factors work one after the other. At the end of the chain, bleeding stops

→ If one clotting factor is missing or does not work, clots will not form properly and bleeding will continue

BLEEDING DISORDER WORD FIND

B	C	N	I	N	E	F	M	U	S	C	L	E	S	R	F	A	C	T	O	R
L	L	M	T	R	E	A	T	M	E	N	T	N	I	M	E	J	D	J	S	E
V	O	N	W	I	L	L	E	B	R	A	N	D	D	I	S	O	R	D	E	R
E	T	U	D	E	F	I	C	I	E	N	C	Y	T	L	E	I	I	O	V	F
E	S	S	H	A	E	M	O	P	H	I	L	I	A	D	A	N	S	I	E	I
H	E	R	E	D	I	T	A	R	Y	E	I	G	H	T	T	T	O	N	R	C
D	P	R	O	P	H	Y	L	A	X	I	S	I	N	D	M	S	R	T	E	I
B	L	E	E	D	I	N	G	H	S	L	V	C	H	R	I	S	T	M	A	S
C	L	A	S	S	I	C	A	L	K	M	O	D	E	R	A	T	E	S	S	N

Bleeding	Eight	Mild	Severe
Christmas	Factor	Moderate	Treatment
Classical	Haemophilia	Muscles	Von Willebrand disorder
Clot	Hereditary	Nine	
Deficiency	Joints	Prophylaxis	

