



### "MY LIFE AS A HAEMOPHILIAC" - by Stuart Chamberlain

The life of a haemophiliac is jam-packed with challenges and uncertainties but I have never seen myself as "disadvantaged". I always relished moments to prove people wrong when they say "no, you're a haemophiliac, you can't do that".



The key to get on top of haemophilia is to not treat your children like they're made of glass, although there are definitely things a haemophiliac shouldn't do - there are lots they can. I've grown up like a very normal kid and my parents have always made sure they didn't hinder my childhood by being overprotective and let me learn many of the lessons by myself.

I've done things most haemophiliacs would never think of doing like paintball and although this might seem like a bad idea, I

had the best time of my life and I didn't end up with a bleed.

I'm not saying let your kids do anything they want, but loosen the reins on your child. If you keep stopping your child from doing activities it will start to affect their minds and they will believe they are made of glass. I have had a very athletic childhood. In primary school I played sports including cross country and soccer. Many people told me I should not be playing soccer and I think they are wrong because as long as you warm up and stretch before every game and practice your body can handle it. In high school I started new sports: athletics, squash, and rowing which changed my life. Rowing needs discipline and is very demanding - with training between 5 and 12 times a week. It put me into great shape and I developed muscle and the number of bleeds decreased. I got to enjoy life a lot more. Rowing has really changed my life and has made me feel like haemophilia is no longer taking control of my life I am taking control of it. I have been rowing for 6 years now. I received half colours and had the



honour of being the rowing captain. Now that I'm in university I've won Gauteng championships and South African Championships. In my 1<sup>st</sup> year at Tuks I got voted as vice-captain. Sport has opened many doors and has played a big part of my life and I think haemophiliacs can achieve great things with hard work and having a positive outlook on life. Being active and keeping in shape is one of the best ways for a haemophiliac to try and reduce the number of bleeds and ensure they live as normal a life as possible.

There are many challenges I have faced in life and it has not been easy, I was afraid of telling people I had haemophilia because I thought they would think I'm weird or not want to be friends with me, and as I've grown up I now realize if anyone thinks that, they don't deserve to be part of your life. By telling people it lifts a great weight off your shoulders and most people will respect you a lot more for telling them. There are also times within one's life when they don't feel like treating themselves and postpone treatment for a couple of days, but I've found that treating yourself as soon as you feel a bleed has only positive effects as it will ensure the bleed is over in the quickest time possible and the pain you will feel will be at a minimum. Never be embarrassed about being a haemophiliac but rather embrace it and accept the fact that you can't change it.

As you can see the life of a haemophiliac



is definitely not all doom and gloom and it can actually affect you very little if you ensure that you keep on top of it. Ensure you live your life to the fullest and never let it get you down. Be strong and positive and you will live a very long and happy life with many amazing moments and ensure you stay on top of haemophilia and don't let it control your life. Remember life is never as hard as it seems.

### *Update:*

Stuart was selected to race for Tuks in the University Boat race at Port Alfred on 15 September 2012. His fellow crew members included one of the Gold medalists at the London Olympics and 5 other oarsmen that have represented South Africa.

In appalling conditions they won the event and beat UCT by 5 boat lengths.

### **Want to study? You can apply for a bursary with the CHF**

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If you want to study next year (i.e. 2013), and you are struggling to find a bursar to fund your studies then the CHF invites you to apply for limited financial assistance.

*Applications  
must be received by  
15 November 2012.*

### Application Requirements

1. Applicant must be a Haemophiliac.
2. Applicant must be physically capable of completing the course of study, and doing the chosen job at the end of the day, taking into account your Haemophilia condition. ie: No physically intense jobs that would be

- severely affected by bleeding episodes.
3. The institution of study must be a residential university or registered, recognised institute of study.
  4. Applicant must provide a full CV.
  5. Applicant must provide a letter from the tertiary institution stating that you have qualified for the course and obtain a provisional acceptance to do the course.
  6. Applicant must provide us with copies of letters sent out to three other companies/institutions requesting financial assistance - The Foundation does not have large amounts of money for education assistance and so is therefore a last resort. You will only be considered for assistance if you can show us that you have done your very best to obtain a bursary elsewhere.
  7. Applicant must provide the Foundation with a letter from the chosen institution of study illustrating all the costs of the course you intend doing.

#### Bursary Rules

1. Should all requirements be met then the Foundation - Central Region Committee will vote on whether to grant the bursary. The decision of the committee is final.
2. Money will be paid directly to the education institution by cheque. Any refund **MUST** be returned directly to the Foundation.
3. Money for books will only be provided upon receipt of a written quotation and a full receipt for the purchase of the books is required.
4. No stationary will be provided.
5. Costs to redo failed subjects are for the costs of the individual. Should more than two subjects be failed, then all financial assistance will stop until the subjects are passed.
6. A copy of all results is required after

each exam.

7. Should the Foundation hold any event where volunteers are required, the individual will make himself available. Failure to do so will result in a review of the bursary status.

*Application forms are available from the secretary of the CHF email: [jbandes@mweb.co.za](mailto:jbandes@mweb.co.za)*

#### HOW CAN YOU HELP OUR CAUSE?

- a. Pay your subs to the SAHF and become a member. Contact secretary Erica Bradley on [jbandes@mweb.co.za](mailto:jbandes@mweb.co.za) or 0834532200 for membership forms
- b. Support our fundraising efforts during the year eg. Dance 4 PWH
- c. Chat to your company about us. We can provide them with all the relevant certification so that they can receive tax benefits and BEE points when making donations.
- d. Raise awareness in your companies or participate for PWH in public events.
- e. Follow us on Twitter @HaemophiliaSA
- f. Follow us on Facebook

[www.facebook.com/groups/401785716506736/](https://www.facebook.com/groups/401785716506736/)

**PLEASE NOTE:**  
GOOD NEWS!! WE HAVE MANAGED TO FIND A SPONSOR FOR TRANSPORT TO & FROM THE AGM/CHRISTMAS PARTY. REMEMBER TO BOOK BY SENDING YOUR REPLY SLIP TO YOUR CLINIC OR [jbandes@mweb.co.za](mailto:jbandes@mweb.co.za)

## East London Camp

For those who enjoy the outdoors, there will be a camp organized by the Eastern Cape PWBD. The camp will be held in East London or Port Elizabeth from 21-23 March 2013.

Topics discussed will include:

- Self management
- Importance of keeping fit
- How can I make a difference

There will also be time for relaxing, braaing, getting to know other PWH, and lots of games and activities.

For more information, contact Henry Steenkamp on e-mail at [steenkamp.henry@gmail.com](mailto:steenkamp.henry@gmail.com)



## Baby & Toddler tips

Here are a few tips for parents of toddlers with Haemophilia:

- Gates blocking stairs are a good way to avoid falls.
- Netted crib covers assist in avoiding falls out of bed.
- Place non-skid strips on the floor of the shower or bathtub. Help your child in and out of the tub until the child is old enough to manage without falling.
- Sew padding into the knees and seat of your toddler's pants to reduce bruising.
- Make sure your toddler wears shoes to protect his feet. High top sneakers provide good ankle support.
- Athletic elbow and knee pads also help to protect against joint bleeds caused by falls.

- Enroll your child in the Medic Alert system.
- Talk with other parents about their ideas about safety measures.

Source: <http://www.hemophilia.org>

## **AGM/CHRISTMAS PARTY**

Please remember to put pen to paper and fill out the reply form (from last newsletter) for the AGM and Christmas Party to be held on Sat 24 November 2012. Kindly return the form to Erica Bradley BEFORE 10 NOV '12 by handing it in at your local clinic, emailing to [jbandes@mweb.co.za](mailto:jbandes@mweb.co.za) or faxing to 0114632347.

We need to know numbers for catering and Christmas presents! So - don't miss out!

**PLEASE NOTE:** Transport will be provided from Chris Hani, Charlotte Maxeke & Steve Biko!



## Educational workshop to be held in Johannesburg - Don't Miss Out!

A haemophilia educational workshop will be held at the OR Tambo Protea Hotel on Fri 16 & Sat 17 November 2012.

All welcome! Conference fees are R260 pp per day. Lecture topics include:

- Psychological aspects of Haemophilia
- Approach to a child with a Bleeding Disorder
- Role of Physiotherapy in Haemophilia Care
- Sexual Health in PWH
- .....and much, much more!!!!!!!!!!!!!!

To register, please contact Judy Butler (012)7857140 or [butlersr@iafrica.com](mailto:butlersr@iafrica.com) or 0837117287

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