



PWH Newsletter

Central Region

February & March 2012

World Haemophilia Day - 17 April 2012

Once again, World Haemophilia Day will be celebrated on 17 April 2012. Various celebrations will be held on the following dates and we look forward to see you there:

Mpumalanga:

Matikwane - 17 April

Rob Ferreira - 18 April

Ermelo - 24 April

Limpopo:

Pietersburg - 28 April

Gauteng:

Chris Hani Baragwanath Hospital - 18 April

Steve Biko Academic Hospital - 17 April

Don't let Haemophilia rule your life -

Erika Walter

My son is now 13 and has severe Haemophilia A. Over the years, our family has been through a lot but at no time have we allowed our son's disorder to win. By win, I mean win emotionally, as at 13 he has had 4 ports, Yttrium into his ankles which are now arthritic and we plan to do his elbows in February 2012. The physical results of Haemophilia may be difficult but they are not a handicap unless you allow it to be. So the way to win is to put life first and Haemophilia second. This attitude has to go into all aspects of your son's life, from school to exercise to recreation.

Along the way we have learnt a few things that we believe can help families rise above the negative and look to the horizon. They are:

- Get to know your medical staff, they are the key to healthy living;
- Surround yourself with friends and family who will not treat your child differently from others. Through them your child will realise that he is

completely normal;

- Keep the injections public; don't hide them away from others. All our son's friends have seen our son being injected. This shows them a bit of what our kids go through and with most kids who have the fear of needles, your son will get an ego boost for handling it well;
- Allow your child to experience life. You must let them try things in a responsible way, but they will fall down but you just smile and pick them up;
- Get involved with their school and the teachers and push your child to succeed. If they see that your child is putting in the effort, they will help where they can. Don't let your child use his condition as an excuse, ever.
- Do family exercise with your son. This will keep them responsible and also allow you to be close by. As a family we do mountain biking. It's great exercise and have relatively low impact against energy expended;

I know that there is no one size fits all approach and you will need to find your own path but in doing this, my last bit of advice is to never hide away from your son's condition. Confront it and deal with it. It's the only way to a good life.

**Please contact
Sr. Alice on
082 896 3833 for
more information
regarding the
WHD celebrations**

My story - Tebogo M Mphahlele

I come from a community where anything unusual is associated with witchcraft and haemophilia is unusual and is still even today. People, young and old would stare and start whispering as soon as I appeared limping from a different joint this time. This made it very difficult to be around people. In our area boys were taught to be tough, i.e. hunting and going to the initiation school and I was the odd one out. I was undermined about everything, couldn't play soccer, the only sport for real boys offered at schools, while corporal punishment was the only thing I could not avoid and this resulted in me missing lots of schooling combined with my spontaneous bleeds.

As if this wasn't bad enough, due to division of our country at the time, treatment was very far from my place (+500 km) and I did not qualify to be at any hospital. Most of the time I sat and waited for bleeds to heal on their own no matter how hectic. Though with limited education and understanding about Haemophilia, I had the best support from my family of which I'm very grateful for, if it wasn't for them I think I would have dropped out of school a long time ago.

I have realized that Haemophilia is for intelligent people, no matter how many days/weeks of school we miss, we always come back and catch up and even excel more than others without any special tuition.

N.B I was never ugly, I was just in pain!!!

Enjoying Life as a Bleeder - Clerment Sefojane / Matthews Paseka

One of the Haemophilia patients from the Free State, Bloemfontein Clerment Sefojane, is a severe Haemophilia A patient. He explains how he enjoys his life despite that he is a bleeder. "I have been a patient all my life" he says with a smile, he further explains that Haemophilia has not changed his life. He has always been a careful young man that he says I have not been in a life threatening situation before. Clerment also believes that one should work hard in life, so that they can live the life that they wish to live.

Clerment says he has a good life and that's all because of good friends." I've had a good life despite my condition,

and I think that's because of the unconditional love and support, I got from Family and Friends." He further elaborated that "nah haven't been discriminated in fact I really enjoyed my childhood." He says with a smile. Clerment studied Safety Management at Unisa, and he currently works as a Label Manager at Music Affair Records and he enjoys his work.

Clerment emphasized the point of going to school and working hard in life, in order to be successful. So brothers let us not allow Haemophilia to stand in our way of achieving our dreams, let's work hard and be the best we can be." He said.

Exercise is very important to PWH. It builds and strengthens muscles, which leads to fewer joint and muscle bleeds!

Famous People with Haemophilia - Leonie Engelbrecht

Famous people who suffer from genetic disease such as haemophilia have often drawn great public attention and curiosity. The success of such people has inspired members of the society to pursue excellence in their areas of specializations.

The Royal Disease:

Haemophilia, also known as "the royal disease", is a genetic related blood disorder that takes blood abnormally long to clot. Haemophiliacs therefore tend to bleed longer after an injury compared to people without the condition. Tsarevitch Alexei, a Russian prince inherited haemophilia from his mother, one of the daughters of Queen Victoria.

Political Leaders:

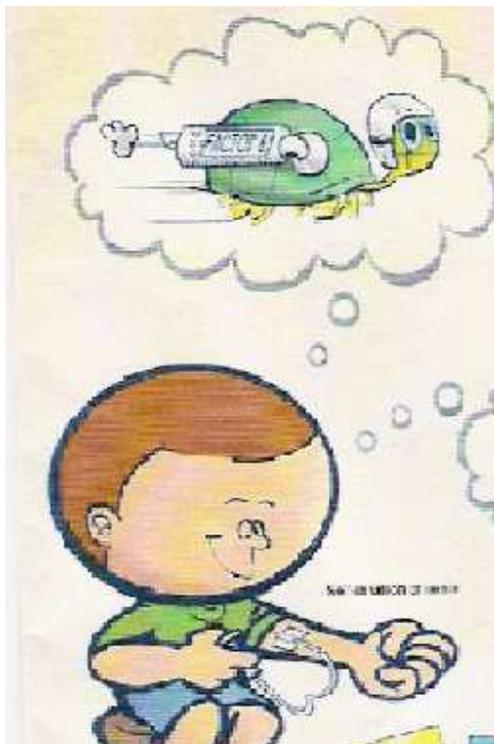
Great political leaders of the past such as Ghengis Khan and Abraham Lincoln are rumoured to have suffered from haemophilia.

Abraham Lincoln reigned as the first President of the United States for close to four years. He is favourably remembered for giving great leadership directions during the Civil War and for his Emancipation Proclamation that led to the freeing of Confederated slaves.

Ghengis Khan was a great warrior and tribal chief famous for subjecting millions of people to suffering and death through his brutal military attacks during the thirteenth century. Ghengi's firm empire lasted over one hundred and fifty years after his death.

Active Campaigners:

Ryan Wyane White a haemophiliac American teenager is famously remembered for his campaigns against HIV and AIDS. Ryan surprised the public by living five years in excess of what doctors had predicted and died in 1990.



Visit our website
www.haemophilia.org.za to
download our new Haemophilia
Pamphlets. It is available in all
11 official languages.

**PLEASE SET YOUR TELEVISION
RECORDERS FOR THE MORNING
OF 18TH APRIL. AN INTERVIEW
REGARDING WORLD
HAEMOPHILIA DAY WILL BE
AIRED ON ETV SUNRISE.**

Please tell us your story. We
will publish it in the PWH
newsletter regardless of your
language. You can forward it
to leonie@lampets.co.za

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**21 APRIL
10H00 START**

DANCE 4

**PEOPLE WITH HAEMOPHILIA
P W H**

2012

**LATIN AMERICAN
BALLROOM
SOLO LATIN
SOLO NRG
SOLO CLASSIC**

**'ALL DAY
COMPETITION'**

**TICKETS: R 50 P/P
Children U/12 Free
Pensioners 50%**

BERARIO RECREATION CENTRE Dolores Ave, cnr King Str, Berario

**For more information, contact event co-ordinator: Erica 083 453 2200, or
jbandes@mweb.co.za**