



“HAEMOPHILIA PATIENTS KEEP ME SANE” – by Matthews Menyau

As a young woman, Ethelwyn Remmers, better known as Ethel grew up in Thabazimbi, with her parents and three siblings, two sisters and a brother. As the eldest she had to lead by example, and make sure that she sets a good example to her siblings, Ethel matriculated at the Pretoria Afrikaans Meisies Hoerskool in 1964. She graduated at the Pretoria Physiotherapy College in 1967 and since then she has never looked back.

Ethel has worked for more than twenty years as a physiotherapist, but the highlights of her career are found within the 15 years that she has worked with the Haemophilia Foundation. “I have learned a lot from the foundation, I wouldn’t be what I am today, if it wasn’t for the foundation.” She says with a smile

Haemophilia Patients keep me sane, she also described herself as an unconventional person, “I don’t do what the book says, I adapt to the situation and take decision from there, treatment first and registration later, this is my motto.”

She also gets cross when patients don’t get proper medication, that’s how emotionally attached she is to the patients. Throughout her experience she has learned that there’s often drama with haemophiliacs, and when there’s drama you have to act quickly.

Despite losing five Haemophilia patients, three of them due to negligence or lack of knowledge by some Health Care providers, that has not discouraged her into

compromising her work. “The death of the five boys made me to be more dedicated to my work; I told myself there should be no patient dying again because of negligence or lack of knowledge. That is why I decided to be more vocal about Haemophilia.” She said

After being involved with the South African Haemophilia and helping start a Haemophilia Clinic at the HF Verwoerd Hospital, now known as Steve Biko Academic Hospital in 1997. She recently had to go into retirement as she has reached 65 years, but she says she will always be a part of the Haemophilia Community “I can’t just drop the foundation, it has taught me so much, I learned so much in life and attended prestigious events. That for me is a life time experience, so I feel like there’s still more for me to do in the Haemophilia Community, and I am still going to be actively involved in the Haemophilia World” She said.

The love of her life, Mr. Ronald Remmers is proud of his wife and the commitment she has given both her profession and family, “It’s was nice to seeing my wife specializing in something she likes, and still being able to make time for her family.”

Mr. Ronald explained his wife as someone who has a lot of capacity for work, so even she’s at home, she always finds something to do.

**If you want to visit our
Twitter Account please go
to
@HaemophiliaSA**

THANK YOU – Central Haemophilia Foundation

The Central Haemophilia Foundation would like to thank Tony Roberts (SAHF) and Anne Duffy (Irish Haemophilia Foundation), for giving up their time on Saturday 1 September to share their psychosocial knowledge with Social Workers, Nurses, Parents and PWH. Treatment for haemophiliacs in South Africa can only get better - thanks to their efforts.



Delegates attending the Psychosocial Conference on 1 September 2012 – Irene Country Lodge

Touched –By Sr Thabi Mnguni

I was touched by Mr Timothy Nsamba's story that appeared on the Newsletter dated Dec 2011/Jan 2012.

The fact that he was homeless and not having treatment for his Haemophilia condition made me realize how some of us do not appreciate the smaller things in life. I'm pleased that now he is receiving the best treatment and is having a loving supportive family.

I was introduced to the SBAH Haemophilia Health team by Sr Kate Bester in 2006 and have never looked back.

She taught me how to give the best service promptly and adequately. I'm presently a Haemophilia Committee member. It saddens me to observe how the PWH are being misunderstood. It only takes one about 20-30 minutes to assist the patient with the administration of medication and only about 5 minutes to attend to their queries telephonically. Hopefully the annual Haemophilia Awareness campaigns will help the Health Professionals to understand the situation better and help to improve the service.

In our clinic we are blessed to have Paseka, the mild haemophiliac who captured the SBAH Haemophilia awareness campaign in April with his video machine. Thanks to the two of you.

I would like to thank Dr J.C. Opperman, who is the pioneer of the Haemophilia Clinic at SBAH, Dr J Potgieter and all the members of the Haemophilia health team for the best service that is being rendered in Pretoria and neighbouring provinces.

CONGRATULATIONS!!

The CHF would like to congratulate Rico Schutte (PWH) from Port Elizabeth who took part in the Police Chess National Championships. He achieved 2nd place and also his national colours!!

I'm A Survivor - by Tshidiso Diedricks

I am a person with Haemophilia B, factor XI deficiency also known as Christmas disease. Just like many of my peers, I was diagnosed when I was only 2 years old. At that age, I would imagine that I bruised quite easily as I learnt to crawl and walk. I was born and brought up in Kimberley under the guardianship of my grandmother who has since passed on (may here soul rest in peace). I believe my two uncle's died as a result of Haemophilia complications.

My family has little understanding of Haemophilia, so their knowledge of raising a child who has a bleeding disorder was a nightmare. As a growing boy, I had severe nose bleeds, spontaneous bleeding and my family would try various muthi's just to stop the agony and pain I was going through. My mother would watch me helplessly when I woke up with a bleed in my ankles, elbows or knees. Back then, it was a taboo in the community for any mother to give birth to a child with abnormal bleeding conditions.

Occasionally, members in the community would visit my house to offer prayers, hoping the misery and pain endured by my family would stop. As a person living with Haemophilia, I was admitted to hospital quite frequently and Kimberley Hospital was like my second home. I got used to hospital beds, drips and needles at a very young age. Doctors and nurses were all too familiar with my condition and sometimes Haemophilia was referred to as the Royal Sickness.

I started school normally, just like all other children, but sometimes I would miss class from a prolonged bleeding period. Due to my physical condition teachers would exclude me from sporting activities and I would not do what boys of my age would normally do. Teachers were sensitive over my condition and older boys teased me as this sick child who always received preferential treatment from the Headmaster. Often these sentiments tarnished my self confidence and I avoided fights as often as I possibly could.

Later, in life I had to come face to face with the harsh realities of a person living with Haemophilia. Haemophilia is a life threatening condition and it can be dangerous if not managed or treated promptly. I had to plan and adjust my life accordingly, also avoiding certain lifestyles. I live a normal life, do things within reason. I am much more informed now than 20 years ago. I have a better understanding of my body.

I treat a suspected bleed immediately to prevent future complications.

Haemophilia treatment and care has improved significantly over the years as we enjoy a long life with quality health care. Fortunately, we all receive safe blood products and thanks to all dedicated doctors and nurses who ensure we have sustained quality health care. It can only get better.

I'm a survivor!

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



**SURO
(STEP UP
REACH OUT)**

We are thrilled to announce that Matthews Menyau - one of our young haemophiliacs from Pretoria, was nominated out of hundreds of entries from around the world to go to San Francisco, California in September 2012 on a SURO (Step Up Reach Out) course for young haemophiliacs.

SURO is an international leadership programme designed to help build tomorrow's leaders in the bleeding disorders community.

We would like to wish him 'Bon Voyage' on this exciting journey and we look forward to him being a leader for our haemophiliacs in South Africa in the future.

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

AGM/CHRISTMAS PARTY

Join us on Saturday 24 November at 10H00 for our AGM and Christmas Party for Haemophiliacs, to be held at the Berario Recreation Centre.

Please fill in and return the attached/inserted reply form.

We would love to see you there!

Come & meet other haemophiliacs and their immediate families as well as enjoy lunch and get a Christmas surprise for haemophiliacs.

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 or 0834532200 for membership forms
- b. Follow us on Twitter @HaemophiliaSA
- c. Follow us on Facebook
www.facebook.com/groups/401785716506736/
- d. Support our fundraising efforts during the year eg. Dance 4 PWH
- e. 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.
- f. Raise awareness in your companies or participate for PWH in public events eg. 702 Walk The Talk, Cape Argus or 94.7 Cycle Challenge

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