



People With Haemophilia Newsletter

Central Haemophilia Foundation

3rd Quarter 2018

WFH World Congress 2018

Glasgow, Scotland, May 2018

By Tebogo M Mphahlele, Deputy Chairperson,
Central Region



I had the opportunity to attend both the WFH (World Federation of Hemophilia) National member organizations (NMO) training and the World Congress held in Glasgow, Scotland during the month of May this year.

As I stepped on the plane excitement and uncertainty clouded my mind! I was excited for being granted the opportunity to represent the SAHF at an event of such magnitude and uncertainty because I didn't know what to expect or what's expected of me. I did not want to misrepresent my organisation or myself.



WFH Choir

Upon arrival in Glasgow I met with a couple of candidates who were attending the NMO training.

As we headed to the Golden Jubilee Hotel, oh what magnificent scenery! Our training commenced from 16 to 19 May and there was so much vital information to grasp. One thing that was common was that although we come from diverse backgrounds with different cultural beliefs, we all have one vision, "safe and effective treatment for all". We were put in different groups and attended well organised and presented trainings on: Volunteerism, Fundraising and crowd pulling and VWD (von Willebrand's disease). I realised that some of the stigmas associated with bleeding disorders in South Africa were not as bad compared to those in the Middle East and most African countries. During the VWD training my team was given a task to draw a person with VWD and identify three common bleeding areas- we agreed on soft tissues, nose and abnormal menstrual bleeds and my team mentioned how taboo it was in their culture to mention menstrual bleeds!

On Sunday 20 May, we were transported from the country side to Glasgow City for the World Congress at the Scottish Science Centre. We checked in at Blu Radisson Hotel next to the City Central Station. Although this was not a sightseeing trip, I could not help wonder how beautiful Scotland was! A choir of candidates from around the globe performed at the opening ceremony and a Scottish piper reminded us of the rich Scottish culture.



Traditional Scottish Bagpipers!

Thomas Sannie was awarded with the prestigious "Frank Schnabel Award" for his outstanding work and I believe we all should strive to achieve this in our life-time. Paralympian Jack Bridge (Haemophilia A) gave a speech of hope and inspiration that Haemophilia does not equal limits! Speeches were given by the WFH president, CEO and City of Glasgow Mayor to name but a few!



Enjoying Scottish cuisine with fellow South African delegates and me at the congress!

Between Monday the 21 and Thursday the 24 I attended many presentations including "Dental and Mouth Bleeds" with our own Sr. Nombuyeselo, "Selo", sitting on the panel.

On Friday 25 I attended the General Assembly with Bradley Rayner, National Chairman SAHF, gaining knowledge from him as we sat through the sessions.

I would like to humbly thank the SAHF, CHF and everyone involved in entrusting me to take part in both the NMO training and WFH World Congress.

To the Haemophilia community let us conquer any situation and rectify social ills associated with bleeding disorders, cultural stigmas, lack of treatment, lack of knowledge and patient support – *"we need to stick together and tackle it head on, not in isolation"*

AGM AND KIDS PARTY

24 NOVEMBER 2018

Join the bleeding disorder community at our AGM

Where? School of Achievement
Corner of Bloemhof Rd & Heidelberg Ave
Elspark, Germiston

GPS Co-ordinates: 26.2599° S
28.2187° E

What Time? 10h00 – 13H00



Talks by: Cobus Visser – Kilionpurpose
(climbing the mountain)

**Dr Paula Fernandes – My child was diagnosed with Haemophilia-
What now?**

RSVP? Please RSVP as we need numbers for lunch and transport
BEFORE 3 NOVEMBER 2018

e-mail juliemal@mweb.co.za

Or fill in the list at your local clinic

Who can come? All people with bleeding disorders, their immediate family and their children – there will be entertainment for the children!



South African
Haemophilia Foundation



Climb with Purpose! Cobus Visser

Kilimanjaro 9-20 July 2018

Congratulations to Cobus Visser and his team of 8 climbers who attempted Africa's highest peak in July 2018! This was no easy feat as Cobus is a hemophiliac who has battled his whole life with painful ankles, knees and elbows!



Cobus first decided to challenge himself after seeing a documentary about Kilimanjaro a few years ago. This inspired him to take the challenge and be an ambassador for people to overcome their own disabilities and struggles in life!

The climb took 7 days in total but Cobus says the first day was the hardest! At this point he thought he had made a huge mistake and was not up to the challenge. His year spent training, hiking and swimming would prove to be invaluable but Cobus says his strength of mind was the thing that kept him going and told him not to give up!



Each night at camp Cobus would give himself 4000IU of Haemosolvate. At the end of each day his joints were sore and tired but he didn't have any bleeds!

By day 4 they reached base camp and that night would be the final climb to the summit, Uhuru Peak at 5895m above sea level. With porters and guides at hand and with his walking sticks and crutches this would be a grueling and difficult climb. It was dark, steep and rocky but they reached Stella Point at 5756m. Cobus was finding it hard to breath and was worried about altitude sickness. The air was so thin!

With only a short climb to reach the summit he decided he couldn't risk it as his breathing was becoming more difficult. The decision was made to make it back to base camp with the help of the porters and a stretcher. The rest of the group made it to the summit!



Cobus at Stella Point 5756m

He was then airlifted to St. Joseph Hospital in Moshi where he recuperated from altitude sickness and regained his strength.

Congratulations on your epic climb and we look forward to reading your book about your experience.

Cobus has set himself a challenge for next year already, The El Camino Walk in Spain and Portugal!

We know you will succeed!



Events Around the Region



From 20 -23 August 2018, a total of 20 nurses from Limpopo and one nurse each from Botswana and KZN were trained in Polokwane. They were trained by Sr. Tuswa and Sr. Anne-Louise

Cruickshank to ensure optimal treatment for all people with bleeding disorders in the region.

Port training was attended by 3 families at Chris Hani Baragwanath Hospital on 9 August 2018



A social meeting and "get-together" at Dr George Mukhari Hospital, Ga-Rankuwa was attended by patients.



On 22 July 2018
50 000 walkers took
to the streets of
Joburg to walk the
talk, showcase their
cause, costumes and
team spirit!



THANK YOU FOR
WALKING THE TALK
WITH US AND
SUPPORTING HIKE
FOR HAEMOPHILIA!



WE'LL SEE YOU ALL
NEXT YEAR!



HIGHLIGHTS FOR 2018
AGM And Kids Party!



Saturday 24 November 2018

Inspirational and educational talks
and entertainment for the children!
Come and join your community for
an informative and fun morning!
RSVP before 3 November 2018 at
your clinic or juliemal@mweb.co.za

GET INVOLVED

- Pay your subs to the SAHF and become a member. Contact Julie Malan at juliemal@mweb.co.za for membership forms.
- Support our fundraising efforts during the year.
- Raise awareness in your companies or participate for PWH in public events.
- Contribute to the newsletter. Anything haemophilia-related. Send your article to juliemal@mweb.co.za louiseellwood@me.com
- Follow us on Twitter @HaemophiliaSa
- Follow us on Facebook www.facebook.com/groups/401785716506736/
Visit our website www.haemophilia.org.za to download our new Haemophilia Pamphlets. They are available in all 11 official languages.

Printing of this newsletter is sponsored by Fax Support (011) 791-7988