

## **WORLD HEMOPHILIA DAY 17<sup>th</sup> April 2019**

***“6.9 million People worldwide have a bleeding disorder, 75 % of them do not know it!”***

### **“Reach OUT : The FIRST STEP to CARE”**

#### **PRESS RELEASE April 2019**

(Cape Town): Lets Change the World for ONE PERSON at a time and help reduce the pain, crippling, suffering and even premature death, of those living with a bleeding disorder. Join SAHF during the month of April and particularly April 17, World Haemophilia Day (WHD) to increase awareness of haemophilia and other inherited bleeding disorders. This is a critical initiative with an ultimate goal of ensuring better diagnosis and access to care for those who have a rare bleeding disorder, and yet remain undiagnosed and without treatment.

“We are a world-wide family, united through blood, working together to improve diagnosis and standards of care, supporting one another, and helping where the need arise. That is what family does for one another.” says Mr. Bradley Rayner, National Chairman and volunteer of the South African Haemophilia Foundation (SAHF).

This year’s theme, “Reach OUT : The FIRST STEP to CARE”, brings attention to the millions of people with Haemophilia or von Willebrand disease who live with or know of someone living with a bleeding disorder.

WHD provides an opportunity to talk to family, friends, colleagues, caregivers and the community at large, to raise awareness and increase support for those living with an inherited bleeding disorder.

This year we have two hash tag awareness events to highlight bleeding disorders; viz;

1. Paint one fingernail red and post a selfie on your social media platform using **#CAUGHTREDHANDED #WHD** in support of women with bleeding disorders **@HaemophiliaSA**
2. Take selfies in groups, individually, with pets, wearing a red tie, bowtie or scarf and post on your social media platform using **#REDTIECHALLENGE #WHD** in support of people with bleeding disorders **@HaemophiliaSA**

#### **Looking forward: Advances in Care and Emerging treatment options**

(KZN): “The Medical and Scientific Advisory Council (MASAC) fully supports and encourages research and clinical trials in South Africa. We are aware of the high cost of treatment both financially and also with respect to quality of life, in patients with haemophilia. The current funding model in resource constraint countries like South Africa, limits the quantity of treatment products that patients with inhibitors might have access to. The ability of our patients to join clinical trials has allowed them to benefit from receiving free products during these trials as well as accessing longer acting/novel treatment products which ultimately improves patient quality of life. The research and clinical trials not only helps to reduce cost of the treatment products in the public sector, but increases academic awareness for the doctors and nurses involved. These academics are primary investigators in international multicenter clinical trials, which are then published in high impact medical journals. This is therefore good for the country, health care workers and ultimately our patients”; says Dr Naidoo, MASAC Chairperson.

(Gauteng): “To date several gene therapy development programs for both haemophilia A and B are evolving. All these programs use hepatotropic adeno-associated viral (AAV) vectors, to deliver the transgene in the liver which is then able to produce the missing clotting protein. The results of both FVIII and FIX gene therapy to date have been very encouraging with many patients successfully converting from severe (<1% clotting factor level) to moderate or mild phenotypes (2-50% clotting factor levels). Whilst the safety profile of gene therapy in adults has been acceptable so far, unexpected transaminitis has been observed in a number of study participants. To date gene therapy represent a dichotomy of knowns and unknowns. It is a matter of time before some of the unknowns are clearer”; says Prof Mahlangu, previous MASAC Chairperson and Clinical Haematologist at Wits and the NHLS in Johannesburg.

Learn more about hemophilia and other inherited bleeding disorders, visit [www.haemophilia.org.za](http://www.haemophilia.org.za) or [www.wfh.org](http://www.wfh.org)

(Cape Town) For World Hemophilia Day 2019 and during the awareness month of April, the SAHF volunteers will be organizing various events at their local Treatment Centers, participating in radio / TV interviews and posting on social media platforms.

“Bleeding disorders can be well managed close to the knowledgeable network. Living a reclusive life and being uninformed is not the best option for the sufferer and the supportive community. Reach OUT, it is The FIRST STEP to CARE”; says Rayner, a person with severe Haemophilia.

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**About Haemophilia and other bleeding disorders**

Haemophilia, von Willebrand disease (VWD), inherited platelet disorders, and other factor deficiencies are lifelong bleeding disorders characterized by bleeding symptoms. People with Haemophilia and VWD do not have enough of a particular clotting factor, a protein in blood that controls bleeding, or else it does not work properly. The severity of a person's bleeding disorder usually depends on the amount of clotting factor that is missing or not functioning. People with hemophilia can experience uncontrolled bleeding that can result from a seemingly minor injury. Bleeding into joints and muscles causes severe pain, joint destruction and disability while bleeding into major organs, such as the brain, can cause death. Quality of life and mortality of people with haemophilia (PWH) has not improved as significantly in the developing world as in high income countries due to inadequate management of the disorder.

Prevalence rates:

1 in 5 000 male birth have haemophilia and

1: 1000 population have VWD. VWD occurs with equal frequency among men and women

**About South African Haemophilia Foundation - [www.haemophilia.org.za](http://www.haemophilia.org.za)**

- 1 To provide a fellowship for persons with Haemophilia and similar conditions, for their families and those concerned in their health and welfare.
2. To promote the interests of persons with Haemophilia and similar conditions
3. To strive to facilitate adequate treatment facilities and access to products for the treatment of Haemophilia at the best financial dispensation possible. To this end the Foundation will support the establishment of treatment centres that comply with the requirements of the World Federation of Haemophilia and the World Health Organisation, by facilitating training workshops for healthcare professional staff. The Foundation will support those centres working towards this compliance.
4. To strive to maintain the level of medical expertise in the treatment centres by supporting the training of medical staff through attendance at international conferences, workshops and visits to comprehensive treatment centres abroad.
5. To render its services to persons with Haemophilia in the Republic of South Africa.

**About the World Federation of Hemophilia - [www.wfh.org](http://www.wfh.org)**

For 50 years, the World Federation of Hemophilia (WFH), an international not-for-profit organization, has worked to improve the lives of people with hemophilia and other inherited bleeding disorders. Established in 1963, it is a global network of patient organizations in 140 countries and has official recognition from the World Health Organization.