



People With Haemophilia Newsletter

South African Haemophilia Foundation

2nd Quarter 2021

WORLD HAEMOPHILIA DAY 2021

17 APRIL

As the COVID-19 pandemic continues to be part of our lives one thing is for certain, our bleeding disorder community is continuing to come together and spread awareness about haemophilia and other inherited bleeding disorders!

APRIL 17, 2021 was WORLD HEMOPHILIA DAY. We made sure that the message of adapting to change was sent far and wide in the greater community. Take a look at how we celebrated! Thank you to everyone for your continuing support and to all the health care professionals who help to keep us safe and offer the best care!

#WorldHemophiliaDay
#LightItUpRed
#WHD2021
#redtiechallenge

ADAPTING TO CHANGE
Sustaining care in a new world
WORLD HEMOPHILIA DAY



WHD2021- BOEKENHOUT CLINIC, MABOPANE, GAUTENG TRAINING 13 APRIL 2021



24 health care personnel at Boekenhout Clinic, Mabopane, adapted to change when they attended the World Haemophilia Day training session.

Sr Kate Hill preparing the training

Sr Kate Hill led the training and made sure everyone stayed safe in the outdoor training venue. An overview of haemophilia as well as diagnosis and treatment of bleeding disorders was well received.



RUSTENBURG HAEMOPHILIA OVERVIEW 14 APRIL 2021

April was a busy month with WHD2021 and Haemophilia overview training. 25 professional nurses received training facilitated by Sr Selo Tuswa and Sr Kate Hill at Job Shimankana Tabane Provincial Hospital in Rustenburg on 14 April 2021.



Sr Selo Tuswa and Sr Kate Hill

FACTOR FIRST CARDS

These Factor First Cards are being delivered soon to all HTC's. They will be delivered to each region via the SAHF Outreach Nursing Sisters.



We would like to encourage all persons with haemophilia and VWD to get themselves a card. Please keep in contact with your HTC to find out when they will be available.

Each card will be supplied with a clear PVC pouch to protect the card.

Thank you to Annie and GSH Team, Dr Beverly Neethling and Louise Ellwood for proofing and editing.



CARRY YOUR CARD AT ALL TIMES!



On 3 June the first of a series of 4 workshops on advocacy essentials was hosted and presented in collaboration with Rare Diseases South Africa and Roche.

With the advent of NHI, COVID-19 and new novel therapies in South Africa it is vital that we are aware of how to successfully advocate for ourselves and the bleeding disorder community at large.

Kelly du Plessis from Rare Diseases SA discussed:

■ WHAT IS PATIENT ADVOCACY?

- Intention- give a voice to individuals or an organisation
- Define your target
- Activities include defending rights, collaboration, access to medication and technology and education
- Everyone is an advocate in their own right

■ WHAT IS THE ROLE OF AN ADVOCATE?

- Mediate for best outcome for medications, laws, and access
- Be constantly active! Make a noise!

■ WHERE BEST TO ADVOCATE?

- Share your story and experience
- Educate
- Spread awareness
- Use social media

■ WHAT QUESTIONS SHALL I ASK?

- What are my goals?
- What value does my treatment offer me?
- What criteria must I fulfil to access treatment?

The second session will follow in the next few weeks, and we will keep you posted so you can join the discussion to ensure you receive the best appropriate treatment.

World Haemophilia Day celebrations and home therapy training had to be cancelled on 17 April as a fire broke out the previous day at Charlotte Maxeke Johannesburg Academical Hospital (CMJAH).



The fire broke out on Friday after a storeroom for medical supplies caught fire at around 11:30 in the morning but was contained by the afternoon. Firefighters had to battle the fire externally after a level 3 parking area above the dispensary caved in.



Parking area on fire at CMJAH

At present the Haematology clinic at CMJAH is still closed. Adult patients are being seen at the Chris Hani Baragwanath Academic Hospital (Bara) Haematology clinic on Thursdays. Patients are asked to phone 0828095806 if you will be attending the clinic at Bara. Please provide your name and GT file number. Also please remember to bring all your medication with you.

Paediatric patients are being seen at The Nelson Mandela Children Hospital. Please contact them at 0722430984

The process to follow at Bara Hospital is:

1. First go to Haematology clinic (first floor) to get screened
2. Open a file on the ground floor
3. Once you have a file you can return to the haematology clinic to have your bloods taken and the Doctor will see you.

GET YOUR NEW SAHF T-SHIRT!

We have new SAHF T-Shirts available in such a striking design! They are R100 each which will cover the cost of delivery. This is a limited run so please contact Julie Malan at sahfadmin@haemophilia.org.za to place your order.



Available in sizes S-M-L-2XL

INTERESTING FACTS!

WFH ANNUAL GLOBAL SURVEY 2019 COUNTRY PROFILE: SOUTH AFRICA

Population **58,558,270**

PEOPLE WITH HEMOPHILIA A, B OR TYPE UNKNOWN

2345

% IDENTIFIED PATIENTS

38.1 %

PEOPLE WITH VON WILLEBRAND DISEASE

654

PEOPLE WITH OTHER BLEEDING DISORDERS

233



THE CONVERSATION ON CARE AND TREATMENT FOR WOMEN AND GIRLS WITH BLEEDING DISORDERS (WGBD) CONTINUES WITH THE 2ND WFH GLOBAL SUMMIT ON WGBD! JOIN US JULY 8-10 TO DISCUSS THE REALITIES OF WGBDS WORLDWIDE, AND EXCHANGE ON CARE, TREATMENT, ADVOCACY, AND EMPOWERMENT. REGISTRATION IS NOW OPEN, LEARN MORE HERE: [HTTP://OW.LY/LQLP50EKBYB](http://ow.ly/lqlp50ekbyb)

GET INVOLVED

- 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 sahfadmin@haemophilia.org.za or louiseellwood@me.com
- Follow us on Twitter @HaemophiliaSa
- Follow us on Facebook www.facebook.com/groups/401785716506736/
- Pay your subs to the SAHF and become a member. Contact Julie Malan at sahfadmin@haemophilia.org.za
- Pay with SnapScan



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

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