

## CLINICS

The clinics are all running well and are visited by sisters every week. **ALL PATIENTS WHO HAVE A BLEEDING DISORDER need to keep in contact with the clinics and be seen on a regular basis.** The haemophilia sisters like to see the patients regularly in order that

- regular contact allows for problems to be identified and managed easier;
- they can improve their service delivery to all the patients;
- they can update patients on new advances/ ideas in haemophilia care.

Please contact the clinics directly for appointments at the following centres.

### Groote Schuur Comprehensive Care Clinic (HCCC)

Fridays 08h00-12h00 in E5. Ph Elaine 021 4043084.

### Red Cross Comprehensive Care Clinic (HCCC)

Tuesday 08h00-11h00 in G1. Ph Sr Zainunisa Brown 021 6585185. Emergencies seen in G1 021 6585280. Open 24 hours.

### Tygerberg Haemophilia Comprehensive Care Centre (Paediatric)

One Tuesday per month in C3A clinic in Paediatric Out-patient Department.

Emergencies will still be seen at the haematology ward G3 open 24 hours.

Phone Sharon 021 938 4539.

### Tygerberg Haemophilia Comprehensive Care Centre (Adult)

#### **DAY CHANGE TO TYGERBERG CLINIC**

Third Thursday of each month at 08h00. Please phone Carmen/Clerk X Block on 021 938 5888 for an appointment.

**Please attend your appointments - if you are unable to do so please notify the clinic and rebook your appointment.**

## **SUBSCRIPTION FORM**

### Member information

Name and surname .....

Address .....

.....

Phone: Home ..... Work .....

Cellphone .....

E-mail address .....

Subscriptions are R50 per annum - donations are welcome.

Please complete the subscription form and return to us with your money either by posting it to us at P O Box 172, Plumstead 7801 or by handing it to Sr Cruickshank at the clinic.



**South African  
Haemophilia Foundation**  
Member of World Federation of Haemophilia

PO Box 172  
Plumstead 7801  
Phone/fax: 021-785 7140  
E-mail: butlersr@iafrica.com  
www.haemophilia.org.za

## **WESTERN CAPE BRANCH January 2018**

### EVENTS in 2017:

**NOVO NORDISK HEMOPHILIA FOUNDATION (NNHF) PROJECT:** SAHF has signed an agreement with NNHF for a 3-year project with funding which will include development of the web registry, medical staff training and a youth project. Phase 1 of the web registry has been completed and Phase 2 is progressing well. Doctors, nurses, physios and pharmacists training will take place around SA in 2018. The first medical training will be a doctors training which will take place in KZN. The youth project commenced in September 2017 when 12 youth took part in a weekend workshop in Cape Town under the mentorship of Bradley Rayner and Sameer Rahim. Shady Sedhom from NNHF attended this workshop. The next youth meeting will be 13-15 April, also in Cape Town, with the same group as in September 2017.

**CAPE TOWN ROCK CAMP : 29 Sept - 1 October 2017** A very successful camp took place at the NGK campsite in Noordhoek attended by 15 PWH. Thanks to Adam Schaffers, Bradley Rayner and the team.

**WFH VON WILLEBRANDS WORKSHOP 2-3 December 2017:** This workshop was attended by Louise Ellwood, mother of 2 sons with VWD from Johannesburg and Dr Lariska Haupt from Bloemfontein. Feedback is available on the website.

### 2018 EVENTS:

**HOME THERAPY AND NEW PARENT TRAINING:** Will take place in the J & J Hall at Red Cross Hospital on **Saturday 27 January**, commencing promptly at 08h30. Refreshments will be provided. If you wish to attend please contact Sr Anne-Louise (0827881038).

**WORLD HAEMOPHILIA DAY 2018:** The WFH theme for WHD 2018 is **Sharing knowledge makes us stronger**. We will again promote the Red Tie challenge and include Women with bleeding disorders in the awareness campaign as this was successful on social media in 2017. Awareness days will be held as usual around the country. Please contact your treatment center if you would be able to provide assistance or support on the awareness days.

\*\*\*\*\* IMPORTANT \*\*\*\*\*

It is vital if a PWH is admitted to any hospital or institution that Sr Cruickshank be notified immediately in order that she may monitor the patient's treatment and progress.

**GENE THERAPY:** There has been considerable interest in the Gene therapy trials taking place in various overseas centres which have been widely publicised. These trials have been taking place over 19 months and the results are encouraging. But it must be remembered that they are still in trials and we need to await the outcome, implications and safety issues. This therapy would also have to be approved once the trials are completed by FDA and other regulatory authorities in the countries which make applications. In SA this treatment would have to be approved by the MCC. If you are interested in taking part in trials you need proof of all the treatment you have received and documented bleed records that are kept in your hospital folder to fulfill the trial criteria for selection.

**WFH CONGRESS 2018: GLASGOW, SCOTLAND 20-24 MAY 2018:**

A group of 5 from SAHF will attend the WFH bi-annual congress in Glasgow, funded by unrestricted grants from the pharmaceutical companies. Tebogo Mphahlele from Johannesburg will attend the NMO training part sponsored by WFH. Bradley Rayner, Tony Roberts and Reeshen Pillay will also attend funded by WFH and Sr Anne-Louise Cruickshank will attend as an invited speaker.

**PLEASE NOTE: Head bleeds are the main cause of death in haemophilia. If a headache persists FOR MORE THAN A DAY a PWH should SEEK MEDICAL ADVICE as SOON AS POSSIBLE.**

**HAEMOPHILIA TRAINING PROGRAMS IN 2018:** There will be doctor, nurse, physio and pharmacy training taking place in the regions during the year. Check the website for details.

**All PWH please note: Before having ANY injections please speak to your haemophilia specialist or nurse counsellor.**

**MASAC MEETINGS AND EDUCATION DAY 8-9 NOVEMBER 2018**

Venue to be announced.

**SAVE THE DATE:** The end-of-year party (for children under 12) will take place on Saturday 24 November in the J & J Hall at Red Cross Hospital.

**NB** It has been agreed by the Provincial authorities that in an emergency an ambulance will take a PWH directly to the tertiary hospital. If there is a problem with the ambulance driver contact Sr Cruickshank (082 788 1038).

**TYGERBERG HOSPITAL:** Adult patients please note that clinics will now take place on the third Thursday morning of each month at 08h00.

**DENTAL CARE PWH:** Oral health and disease by Alison Dougall  
It is important for everyone to take excellent care of their teeth and especially people with bleeding disorders. Here is some information from a wonderful dentist in Ireland, Alison Dougall, who is passionate about dentistry and works with people with bleeding disorders.

Oral health is an integral part of overall health. The mouth is part of the craniofacial complex that allows us to speak, chew, smile, laugh, cry, kiss, taste, smell, and swallow. A healthy mouth is free of pain, infection, injury, birth defects, cancer, and other disorders that impact the comfort, function, and appearance of the mouth.

For children and adolescents, the most common oral diseases are dental caries, gingivitis (gum disease), dental trauma, dental erosion, and malocclusion (misalignment of teeth). Dental caries and its common sequelae of pain and infection directly result in poor eating, disturbance of sleep, loss of educational opportunities, and can indirectly affect family life. The psychosocial impact of oral disease can be enormous for the individual, potentially leading to low self-esteem, stigmatization, and increased risk of bullying (1).

World Oral Health Day (WOHD) is celebrated around the world on March 20, every year. It is an international day to celebrate the benefits of a healthy mouth and to promote worldwide awareness of the issues around oral health and the importance of oral hygiene for everyone, old and young.

With 90% of the world's population suffering from oral diseases in their lifetime, WOHD provides hemophilia communities a platform from which to take action and help reduce the overall disease burden of poor oral health on children with hemophilia. WOHD aims to raise awareness of the impact that oral health has on overall physical health and wellbeing. It is a day for people to have fun with activities that make people laugh, sing, and smile, and to help to inspire change. Toolkits and resources for organizations that wish to conduct their own WOHD activities are freely available in several languages ([www.worldoralhealthday.com](http://www.worldoralhealthday.com)).