EVENTS SO FAR THIS YEAR:
PARENTS EMPOWERING PARENTS - 19-21 February 2016: Ed Kuebler, the co-ordinator of the International PEP program, flew from Texas to run a Train the Trainer PEP workshop for SAHF at the Aviator Hotel in Johannesburg. Seventeen parents and nurses participated in the workshop and the feedback has been excellent with the catch phrase Who is the parent? A report and photo will feature in the next national newsletter.

FUN DAY 19 MARCH 2016: Held at the swimming pool at Red Cross Hospital for children aged 7-12. Sr Anne-Louise spoke on self management of haemophilia and Tony Roberts organized educational games. Following this Sameer Rahim and his team of physios took the pool with the participants and great fun was had by all. The water was a little cold but the children did not want to come out as they were having so much fun. We finished with pizza for everyone for lunch. The feedback was excellent and we plan to repeat the event in 2017. Thanks to Chantel Kuture for initiating the project and to Freble and Graham Reid for all their efforts.

WOMENS GROUP 16 APRIL 2016: As part of WHD celebrations a meeting was held at GSH and two genetic counsellors spoke on “Haemophilia carriers - all you need to know”. Sr Cruickshank also spoke on pregnancy in carriers. It was a very informative session.

WORLD HAEMOPHILIA DAY 2016: Awareness days were held around the country and in Cape Town at Red Cross, Tygerberg and Groote Schuur hospitals. Very successful braais were held in Bloemfontein and Kimberley and a Walk for Haemophilia was held in East London. Photos of all these events will feature in the national newsletter.

OVER 21s GROUP 30 APRIL: A braai was held in Wynberg Park, organized by Monty Barnard. Attendance was disappointing but those who were there enjoyed boerie rolls. There is a WhatsApp group - to join contact Monty on 0762022222.

*************** 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.

STEP UP REACH OUT (SURO) PROGRAM: Adam Schaffers, a PWH from Cape Town, was accepted for this leadership program (age group 21-25) in 2015 and has visited San Francisco and Vienna to meet with PWH from other countries and participate in a 3 day leadership program. Adam is now using the skills he gained to encourage and mentor PWH in his community. SAHF is nominating a PWH from East London to participate in 2016. There is a program for older PWH (26-38) AFFIRM and we shall be nominating someone to attend in 2017. Both these programs are sponsored by Bayer.

CAPE TOWN ROCK CAMP: 30 Oct - 1 Nov 2015 A very successful camp took place at the NGK campsite in Noordhoek attended by 15 PWH. Thanks to Tony Roberts and his team. The next camp will be in 2017.

NATIONAL NEWSLETTER: Alex Stewart, a severe PWH, has kindly agreed to be the editor of the National newsletter. He is preparing the next edition now and can be contacted on digipix36@gmail.com if you have any suggestions/articles/photos for the newsletter.

FORTHCOMING EVENTS:

HOME THERAPY AND NEW PARENT TRAINING: Will take place in the J & J Hall at Red Cross Hospital on Saturday 25 June commencing promptly at 09h00. Lunch will be provided. If you wish to attend please contact Sr Anne-Louise (0827881038).

WFH CONGRESS 2016: ORLANDO USA: 24-28 JULY: A group comprising 1 doctor, 3 nurses and a physio, will attend the WFH bi-annual congress in Orlando, funded by unrestricted grants from the pharmaceutical companies. Julie Malan, a parent, will attend the NMO training prior to the Congress and is also a speaker at the congress. Tony Roberts is a member of the psychosocial committee and will also be speaking at the congress. Both Julie and Tony are being funded by WFH.
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 NURSES TRAINING 2016: There will be only one nurses training course this year and that will take place in Pretoria from 19 to 22 September. If you know any nursing staff who would like to attend or if you would like to nominate the sister from your clinic please contact Sr Anne.

RARE DISEASES CONFERENCE: CAPE TOWN 19-22 OCTOBER 2016
This international meeting is taking place at Spier and SAHF will be represented at the exhibition as well as attending the sessions. Awaiting further details of the programme.

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

MASAC MEETINGS AND EDUCATION DAY 3-5 NOVEMBER 2016
The meetings will again take place at the Protea Hotel OR Tambo. Rana Saifi, who has taken over from Assad Haffar as WFH Regional program manager for the Middle East and Africa, will be attending the meetings. Programme still to be finalized.

SAVE THE DATE: The end-of-year party (for children under 12) will take place on Saturday 26 November in the J & J Hall at Red Cross Hospital.

WFH TWINNING WITH MAURITIUS: This is the final year of the twinning partnership with Mauritius.

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 7881038).

GENETIC ALLIANCE OF SA: SAHF is a member of GASA (formerly SAIDA) and their website is www.geneticalliance.org.za.

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 direct for appointments at the following centres.

Grootes 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.

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)
One Friday a month in X Block. Phone Abigail 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.