

WORLD HAEMOPHILIA DAY 2011

Wednesday 13 April 2011

Chris Hani Bara Hospital – Hospital Gate

Friday 15 April 2011

Charlotte Maxeke JHB Hospital – Hospital Street

Steve Biko Academic Hospital – OPD

Potchefstroom Hospital – OPD

George Mukhari Hospital - OPD

Saturday 16 April 2011

Pietersburg Hospital – Stalls in the mall of the North, Limpopo and Savannah Mall

Gauteng Haemophilia Foundation – Dance for PWH – Report by Sr Alice



What a success! The Central Region has celebrated the World Haemophilia Day by hosting a Dance Fundraise Competition for the first time. The event was organized by our secretary Erica Bradley. The morning of the 16th was cold and rainy; we were worried about people attendance, until we were over whelmed by the support we received from the dance club members, the Haemophilia community, the sponsoring companies and the community at large. It attracted about 300 guests, everyone came together to support a good cause.

The daylong event started at 10h00 to 17h00 at the beautiful hall of Berario Recreation Centre. We had 10 free seats for the Haemophilia community; the South African Haemophilia Foundation had a table with continuous information on request. We were all stamped on our wrists as we were coming into the hall. The tuck-shop was continuously supplying us with delicious warm meals that kept the celebration on. Our celebrity guest was amongst the panel of judges, Mrs. Salome Sechele.

We watched from solo dancers to couples ballroom and latin american - all the dancers were brilliant. At 16h00 we had a spot prize which was won by one of the dancers. Kieran Bradley went around the hall with the contribution box whereby people donated generously into the box. This was the best fundraiser ever, not only enjoyed by all, but we managed to raise R18 000.

We all stood up and clapped hands as the SA champions Darren Hammond & Kylee Brown demonstrated to the crowd. Video included. A haemophilia event would not be complete without infusing treatment to one of our boys who fell whilst playing.

Everyone we have spoken to have enjoyed immensely.

Thanks to the organizer Erica Bradley, our celebrity guest Salome Sechele, the SA champions, our sponsors and the volunteers.



Haemophilia Day Programme

The program was put together to consolidate all the knowledge and skills which were brought to this area this year by the Sister Cruickshank & the SA Haemophilia Nurse Committee.

Welcome & Opening Address	Introduce the committee & Dennis Kibiru as chairman of ROCK & make them aware of ROCK	Mr Steenkamp, Haemophilia Nurse for Frere Hospital
Review of the knowledge gained	The idea is to inform the PWH & nurses as to the amount of education which has been done in this area. Encourage participation in future activities such as the PWH camp which will take place in March 2012.	Mr Steenkamp, Haemophilia Nurse for Frere Hospital
Physiotherapy Group Work	Assist nurses and PWH to realise that with limited equipment exercises can be done both to strengthen and rehabilitate joints.	Ms. Pakama Ramatseng, Haemophilia trained physiotherapist & her physio team
Home Therapy Talk & Demonstration	Mr Steenkamp to talk through the process whilst PWH go live with a demonstration of how to infuse factor.	Mr Steenkamp, demonstrated by patients of Frere Hospital Haematology clinic
Management of Carriers during Pregnancy	Dr Knox	Medical Officer, Haematology OPD, Frere Hospital
Demonstration on X-Linked Inheritance	Participants from the audience use X & Y flash cards to enact the inheritance puzzle	Dr Knox & audience participants
Thanks		Senior Nursing Sister at Staff Development, CMH
Prizes & Gifts	Thanks to National Bioproducts Institute (NBI), Novo Nordisk & Pfizer for gifts & prizes	
Tea, Coffee, Cupcakes & Muffins	Thanks to Mrs Steenkamp & Dr Knox for refreshments & eats	



World Haemophilia Day celebration report

The plenary meeting for the celebration of the World Haemophilia Day (WHD) was on 29 March 2011 at Middelburg hospital. The human genetics, haemophilia trained nurses and one Emergency Medical Service (EMS) official attended the meeting.

The group was divided into two commissions to plan on how they are going to raise awareness to the communities and to the health workers. The following were the resolutions from the commissions:

HEALTH WORKERS / COLLEAGUES	COMMUNITY
1. Permission from management	1. Community Radio Stations
2. Venue: OPD/CAS	2. Church Services especially youth
3. Dates: should be before 17 April 2011	3. Advice on circumcision
4. Dress code: Maroon / Red	4. Visiting the schools
5. Talk about Haemophillia: Speaker	
6. invitations to the clinics	
7. Pamphlets and balloons for decoration	
8. Balloons for decoration	
9. If possible a patient with haemophillia	
10. Invitations to allied personnel: physiotherapy	

Letters were written to the District Directors and Hospital Management informing them about the plans for the World Haemophilia Day. The management for Tintswalo and Rob Ferreira hospital were informed on how the event will be conducted in their respective hospitals.

Local radio stations were contacted asking for slots and they were told that the slots should be before the 17 April 2011.

- Radio Kragbron at Witbank gave slot for the 12 April 2011 for 30 minutes. The doctor and the sister from Witbank hospital gave presentation in Afrikaans and in English
- Greater Middelburg FM radio at Middelburg gave a 3 day 30 minutes slot on 13,14 & 15 April 2011. Sr Mthombeni and Sr White gave presentations
- Radio Bushbuckridge gave slot on 13 April 2011 at 10h05 – 11h00. Ms Sparara Masinga gave the presentation.
- Barberton Community Radio (BCR) gave slot on 13 April for 30 minutes after 11h00 news. Sr Thandy Motaung presented at BCR
- World Haemophilia Day was celebrated at Tintswalo hospital on 14, Rob Ferreira on 15, Lydenburg on 18, KwaMhlanga on 14 and Piet Retief on 12 April 2011
- Physical and material support received from Novo Nordisk , adcock ingram and NBI

The representative from Novo Nordisk joined the event at Tintswalo. She brought the following promotional materials:

- ✓ 10 T-shirts
- ✓ Balloons
- ✓ Snack box
- ✓ Juice
- ✓ Simba chips
- ✓ Sweets
- ✓ Aero- plain toy
- ✓ Big Novo 7 banner
- ✓ Stress relief balls
- ✓ Zulu pamphlets on “What is haemophilia”

At Tintswalo hospital, the Out Patient Department (OPD) waiting area was used. A big table was organized at the entrance.

The area was full with clients coming for consulting. The balloons and the big Novo 7 banner decorated the area. Three trained haemophilia nurses (Ms L. Lamola from Rob Ferreira hospital, Ms T Motaung from Lydenburg hospital and Ms SE Masinga from Provincial Office) gave information on haemophilia to the community and nursing staff at the OPD waiting area.

The flip chart was used to draw the family tree and to explain how haemophilia came about in the family

The big haemophilia chart was also used by another nurse to give information to the listeners at the Paediatric Out- Patient –Department open space.

The group of students from the Nursing School also joined the community so as to be informed on haemophilia.

Two parents, a granny and one haemophiliac client attended the celebration.

The parents shared their experiences with the nurses.

The promotional materials were distributed as follows:

The T-shirts were distributed to the presenters and those who assisted with the organization of the area

The balloons decorated the area but were given to children after the event.

The snack boxes were given to the nurse so as to give all haemophiliac clients when coming for their OPD check – ups.

The aero-plain toy, juice and simba chips were given to children in the Paeds OPD

The stress relief balls were distributed to nurses who gave right answers during the questioning session

The pamphlets and other reading materials were given to whoever needed a copy

Support visit to the pharmacist

The dispensary was visited to find out stock levels of Haemophilia Treatment Products.

Support visit to the ward

The sister from Rob Ferreira was oriented to the Paediatric ward.

WHD at Tintswalo hospital Paediatric OPD



WHD, nurses from Nursing School at Tintswalo hospital



WHD celebration at Rob Ferreira Hospital on 15 April 2011

The trained team that was at Tintswalo attended the event at Rob Ferreira Hospital on 15 April 2011. The General OPD was having clients coming to consult. The nurses and the clients were given information on Haemophilia. A lady who had all signs of bleeding disorders was referred to a doctor for screening.

WHD at Rob Ferreira Hospital General OPD



World Haemophilia Day celebration at KwaMhlanga Hospital was on 14 April 2011 at the dining hall

The Chief Executive Officer (CEO) invited the staff for the celebration of World Haemophilia Day. Health workers made some money contributions to be able to buy balloons and to have tea with sandwiches. The dining hall was well decorated. The event went well. The hospital staff attended and asked some questions.

World Haemophilia Day celebration at KwaMhlanga Hospital



The Celebration of World Haemophilia Day at Mkhondo Municipality (Piet Retief in Gert Sibande District) was on the following days:

10.04.2011 – Arise and rebuild church
& at Swedish Free Church

12.04.2011 – Piet Retief Hospital

13.04.2011 – Cana Combined School at Sulphursprings

17.04.2011 – Alliance church – Jerusalem
& at Emmanuel church

19.04.2011 – Vukubone High School in Driefontein

The home visits were conducted and known and unknown haemophiliac cases were identified. The undiagnosed cases were told to go to hospital for screening.

- Pamphlets about haemophilia were distributed to the community
- Posters on haemophilia were plugged in places visible to the community and hospital staff to be able to read .g. Supermarkets, all hospital department notice boards and hospital entrance gates etc.
- Local press media (excelsior) was used to disseminate information to the community at large.
- The nurse contact numbers were given to the community members

Trained haemophilia nurses showed some commitment in awareness raising for community and the medical staff. Some hospitals didn't forward their reports.

WORLD HAEMOPHILIA DAY 2011

WHD in Northern Cape was celebrated in Sutherland, which is more than 700 km from the treatment centre in Kimberley.

Background

We have a little boy who has haemophilia, living in Sutherland and in grade 1. He is hyperactive like all children his age and every now and then he needs to be transported/airlifted to Kimberley hospital with severe bleeds due to injuries. In early March the boy sustained head injuries due to falling from his bed. According to his Mum, he was jumping up and down on his bed and he did not listen to her when she told him to stop jumping. He was taken to the hospital and the sister in Sutherland notified Dr Jooste in Kimberley. Dr Jooste advised that he be transferred to Calvinia hospital which is the outreach centre 150km from Sutherland. The child received his factor and was observed for 24 hours and then discharged back to Sutherland. A week later the boy's head was swollen and Dr Jooste advised that he be transferred to Kimberley where he spent 2 weeks. A scan was done and fortunately it only showed bleeding under the skin not on the brain.

Purpose of WHD celebration in Sutherland

- To give support to the nursing sister who is looking after this PWH
- To teach the Mom home therapy as she requested
- To raise awareness on bleeding disorders, especially haemophilia, in our rural areas in the Northern Cape

The event itself was a great success in spite of major problems at the last minute. We almost did not go to Sutherland and we appreciate the support from SAHF and especially Judy who made the trip possible. Thanks to Kimberley hospital for providing us with a patient transport bus and a combi as well as 3 drivers.

Sr Arends, a trained haemophilia nurse, travelled from Hartswater with one of her patients, a boy of 4, and his mother, and a lady from the Albinism Society of SA Support Group from Pampierstand also attended. From Kimberley we had two cousins with their mothers. A group of nurses from the 2 clinics where our patients are seen i.e. Paediatrics and Reproductive Health, attended with the sonographer. The latter plays an important role when we have carrier mums who are pregnant as she does the sonars to determine the sex of the baby in order that we can prepare in time for the management during labour and after birth, especially if the baby is a boy.

Red jelly was made to celebrate this occasion. We had a float parade through the streets of Sutherland and everyone was dressed in red including the community members. The school children had made a poster in a poster competition a few weeks before the event.

The event was held at one of the school halls and the teachers had organized some activities rendered by the school children. One of the politicians welcomed us to Sutherland and with their blessings we had a very successful event.



PRETORIA

Sr Thabi Mnguni

The WHD Haemophilia Awareness was held on 14 April at Steve Biko Academic Hospital. Great support was shown by :

- The Communications Officer and DJ, Mr Michael Williams, who warmed the event by playing classic music for those attending.
- Our area manager who presented the event in the meeting.
- Our own haemophilia doctors, Prof Opperman and Dr Potgieter and their medical students.
- Representatives from the pharmaceutical companies: Ms Amada Mvubu (NBI), Ms Ashvena Gajathar (Novo Nordisk) and Zeldia from Bayer who contributed gifts which were handed over to those participating.
- A mother and her son who came from Mpumalanga to get help from Stee Biko Hospital.

PROGRAMME:

Haemophilia Overview – SrMnguni

Care to the joints and the prevention of complications – Mrs Ethel Remmers

Thanks to Sr Kate Hill who went all over the hospital inviting people to come to the event, and also to Sr Alice Banze who organized an instant SA mass choir by singing several songs, Gospel and “Gaoswenkela Haemophilia you’ll never come alright” she encouraged the “choir” to pronounce HAEMOPHILIA.

The event was indeed Educational.

KWAZULU-NATAL

1. Awareness at Wiggins Secondary School – to arrange a date with the Principal, Chantal to accompany Sr Phume to school. To promote awareness. Distribute pamphlets, stickers, balloons etc.
2. Newspaper Articles – sent to the Rising Sun, The Tabloid, Zululand Fever and Mum’s Mail. A short article explaining what is Haemophilia together with contact numbers.
3. Radio – Sr Phume was called in by Vicky Masuku of Ukhozi FM – Increase awareness on Haemophilia as Ukhozi FM has a large number of listeners.
4. Ngwelezane – 14th April 2011 – OPD entrance – set up a desk with pamphlets, small talk on Haemophilia.
5. King Edward Clinic – 15th April 2011 (Friday) – Information desk in New block. Everyone to wear red to promote Haemophilia. To hand out pamphlets, balloons, stickers, talk on haemophilia.
6. Greys Hospital – 21st April 2011 – (Paeds) Clinic – Awareness, hand out pamphlets etc.
7. Ushaka Marine World – 16th April 2011 (Sat) – Chantal is planning an eventful day for +- 20 kids including lunch, talk on Haemophilia, visit to sea world.

World Haemophilia Day 2011

WC 2011



WESTERN CAPE

World Haemophilia Day was celebrated in the Western Cape at 4 different venues this year!

The first venue was at the Mnandi Beach resort and was a picnic attended by the haemophilia committee and many families of PWH on Saturday 16th April.

The Braai masters were Bradley, Tony and Greg! There was plenty of cricket played by the boys and a teaching session to some older boys by Bradley and Tony! Bradley and Tony never miss an opportunity to inspire and keep the PWH motivated and sorted!

We hosted 2 WHD awareness days : at Red Cross Children's Hospital OPD on Tuesday 19 April and at Grootte Schuur Hospital Street on Thursday 21 April. Both of these days were well attended by members of the public and the PWH from the HCCC's in the WC. We held a competition for everyone to guess the Queen Victoria family type of haemophilia. Many won prizes for their efforts, even though some got onto the internet to check answers on their mobile phones!! We had not bargained for that!!

A lecture on Haemophilia at Tygerberg hospital to mainly the nursing staff from all departments was well attended by the staff. A Mom with haemophilia told the moving story of how her son was diagnosed and how she is trying to bring him up in as normal environment as she can!

This was followed by a very successful question and answer session with participants in the audience receiving prizes for questions on haemophilia being answered correctly! These prizes to the winners were thrown into the audience causing a huge amount of laughter!!

The Western Cape Haemophilia Foundation would like to thank the Industry partners who were very generous with their support for these events with WHD Badges, posters, as well as prizes and snack contributions etc. to help make these events as successful as they were!

RADIO/TV INTERVIEWS

9 April	SAFM Weekend Live : Prof Mahlangu
12 April	Radio Kragbron at Witbank : Dr and Sister from Witbank hospital
13, 14 &15 April	Greater Middelburg FM radio : 3 x 30 min slots . Sr Mthombeni and Sr White
13 April	Radio Bushbuckridge – Mrs Sparara Masinga
13 April	Barberton Community radio – Sr Thandy Motaung
14 April and 10 May	Tony Roberts SAFM Morning Talk Health matters
14 April	Sr Cruickshank Morning Talk 11h15
14 April	Lesedi FM: Sr Angie Makala
14 April	Jozi FM : Prof P Scott
14 April	Metro FM : Prof Coetzee & Mrs Malan
15 April	SABC1 Kids News : Dr Lindiwe Pemba
17 April	SAFM Weekend Live : Pastor Monametsi
17 April	Channel Islam : Prof Coetzee
18 April	Lotus FM : Prof Jogessar
18 April	Bush Radio Sr Cruickshank with Xoliso
19 April	Andrew McDonald DSTV audio
? –	Good Morning Africa : Alice Banze
24 April	Radio 702 Sunday Early : Prof Mahlangu
26 April	SABC Morning Live : Prof Mahlangu

NEWSPAPERS

13 April	Citizen Free State
14 April	Citizen main edition
14 April	Daily News