



KZN Haemophilia Youth Camp

by Kristy Fowles

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From the 11th – 14th December, I attended a KZN Youth Camp for children and young adults who have a genetic blood disease called Haemophilia, this is a disease where one of the blood clotting factors (usually Factor 8 or Factor 9) are missing and those affected need to inject themselves regularly in order to replace it. Since without clotting factor, one is unable to heal, any sort of mild injury leads to an internal bleed.

This was an educational camp sponsored by the Haemophilia Association of South Africa. The camp was held near Richmond at a place called RoseLands. My husband Wayne, who himself has Haemophilia, is chairman of the KZN Haemophilia Foundation and organized the camp; I went along for support and we were accompanied by Sister Phumi from the Haemophilia Clinic at King Edward Hospital, along with Tony, a child educational psychologist from Cape Town.

I have to admit that this was a challenging experience for me and at times I was largely out of my comfort zone, although this was good in many ways as part of a personal growth experience.

We began our experience by everyone introducing themselves and sharing something with the group. Since only 25% percent of the kids there spoke English, Sister Phumi interpreted for those of us who were Zulu-challenged. There were 20 attendees, the group ranged in ages from 8 to 27 and during our time there we spent a lot of time with the group teaching them how Haemophilia is passed on, how it is treated, cases where some people develop inhibitors (resistance) to the medicine and we taught them the basics of general hygiene before injecting. We also covered fatal bleeds such as cranial bleeds, which kill at least three to four haemophiliacs each year.

On the Saturday, we discussed the importance of prophylaxis, which is treatment before an activity which may cause a bleed. Everyone was weighed and was taught how to work out how much factor they needed for their weight, this is necessary in order to bring their factor levels up correctly, an average of 20% for prophylaxis and 60% for an actual bleed (this may vary depending on the severity of the bleed). Before we began, each person was given a sponsorship package containing a "Changing Possibilities in Haemophilia" T-shirt, a notepad, a pen, a packet of Fritos and most importantly, a quick-release tourniquet (used to constrict veins).

Cont'd on Pg. 2



Cont'd from Pg. 1

Some of them already knew how to mix their medicine and how to self-infuse, but for many, this was their first time. I must say, all the lads were very brave and not one of them cried, in fact, they were surprisingly keen to learn how to mix and administer their medicine themselves, to be independent. What we soon realized however, is that although eagerness was in abundance, education on this front is quite lacking, especially when it came to the importance of not injecting air into one's veins and the necessity of having a syringe ready once the butterfly needle is inserted.

After they had had their prophylaxis, the kids were taken off with the RoseLands Camp instructors and did some team building activities, along with playing a hearty game of soccer. We enjoyed a wonderful bonfire on Saturday night, where some of the kids sampled roasted marshmallows for the very first time. On the Sunday, we took a short hike to the dam and even those on crutches were keen to come along, one of the guys is on the government list for knee replacement surgery.

Overall, the camp was a great success, where new friends were made, support groups were formed, and a few surveys were done regarding the availability of medicine and distance to travel in order to obtain it. One of the greatest lessons that these kids learned is the symptoms of fatal bleeds, along with the importance of prophylaxis, along with an understanding of the history of the disease regarding how it is passed on.

It was amazing to have been part of such an event, and it especially puts a lot of perspective on how blessed I am, when so many others have nothing at all, and on top of it all, a genetic complication. Despite all odds however, these kids never seemed to stop smiling.

If anyone would like to donate towards the KZN Haemophilia association, or would like to help out in some way, please drop Wayne Fowles a mail regarding this : waynefowles@gmail.com

This story indicates how essential it is that home therapy be available to all persons with Haemophilia. Not just the privileged few living near well equipped treatment Centres with competent staff and the opportunity to go onto home therapy! Home therapy would most definitely have been the tool that could have been used in an attempt to prevent this tragic loss of life! Not only must those without Inhibitors have the opportunity to be treated for each and every bleeding episode, but all persons with Haemophilia should have that opportunity! Home therapy is similarly no longer a privilege for some and not others! It also begs the question if the price of a life is cheaper in the rural and remote areas of our beautiful country? Mirriam has left the Johannesburg Hospital to pursue other interests since submitting this contribution. This matter is so important and relevant that the message that it carries is published here although the actual events have transpired some time ago. Mirriam will be remembered for the contribution she made to improve the conditions facing persons with Haemophilia – Ed. →

Home Therapy—A tool to save lives

From a report by Mirriam Mokwena to the Chairman

On Saturday 13th January 2006, whilst still on leave, I attended a funeral of an 11 years old Haemophilia boy, who attended the clinic at Pretoria Academic hospital for his treatment needs. He had inhibitors and was residing in Moloto village, in Mpumalanga - approximately one hours travelling time from Pretoria.

He presented at Pretoria Academic hospital on the 5th January 2006 with an excruciating headache. On arrival he was treated as an emergency, Feiba was administered immediately and a brain scan was ordered. The scan revealed a massive brain bleed, and he was rushed to ICU. The Feiba dose was increased to twice daily, but regardless of all the prompt attention and high care treatment given, he died on the morning of Saturday 7th January 2006.

A very sad event indeed!

Treatment arrangements

Soon after diagnosis in 2004, Haemophilia outreach training and education was organised for the staff of his local hospital and clinic. The first outreach was undertaken in June 2004 at the Kwa-Mhlanga hospital to the medical professionals there. The second was done in September 2004 at the Moloto Primary school to inform the teachers and community health nurses about Haemophilia. The purpose of these efforts was an attempt to arrange for treatment to be available to him nearer his home.

As an example of the arrangements required in the case of people living in remote areas, the following advocacy and care was arranged for this boy:

- I liaised with the Provinces' Directorate of Health. The co-ordinator, understood the situation and she was supportive in assisting with the arrangements for the lecture given to the doctors in the Kwa-Mhlanga hospital.
- She also arranged funding for a nurse from the Kwahlanga hospital to attend the Haemophilia nurse training program during the July 2004 sessions. At this stage there were 2 boys with Haemophilia in the area of the Kwahlanga Hospital.
- The Social workers and teachers applied and arranged for the boy to be admitted to a school for the physically disabled in Pretoria, where he was scheduled to be admitted in January 2006.
- A child support grant was granted as a relief for the family.

"...he presented at the Hospital with an excruciating headache, was treated in ICU, but it was too late and he died two days later. A very sad event indeed!"

What went wrong?

Despite all these efforts to ensure that the best possible treatment facilities be available to him, the boy could not be on Home therapy because:

- The local Community Hospital indicated that they could not afford expensive treatment on the tiny budget allocated to them. They thus referred the patient to their Provincial Hospital every time he came in for treatment. This caused time delays as the Provincial Hospital was situated three hours travelling time away. Immediate treatment was thus not available when the patient needed it.
- The Policy of Pretoria Academic Hospital does not allow for patients coming from outside the service area borders to be given factor to take home.
- In the case of Inhibitor patients as was the case here, the treatment remains very expensive. To contain costs the hospital only treats such patients, when presenting with a life threatening bleed.

This patient had a cerebral bleed, which started the previous day. We were told he cried with pain, and requested for ice to be applied on his head the whole night. His grandmother was away to collect her monthly pension grant at the time. There was no money and no one to take him to Pretoria during the school holidays at the time. The next morning, he had to walk a long distance to catch the bus, accompanied by his aunt. By the time he arrived in Pretoria he received all the correct attention and medical treatment, but it was too late to save his life.

Conclusion

I asked myself what the outcome would have been if somebody had got him an Ambulance on that very first night. Would he have survived? Somehow I do not think so, because it would have taken him to a hospital in Mpumalanga where Feiba was not available, and he would have died anyway.

The question I am asking myself is:
"Do the rural Haemophilia patients have a chance?"

Mirriam Mokwena.
Haemophilia Nurse
Outreach training and Education programs

Overcoming Obstacles

by Irma de Villiers

I am writing as mother of Jean de Villiers, 36 years of age and a person with Haemophilia with inhibitors who has been a patient at the Johannesburg Haemophiliac Clinic for many years.

Jean survived 3 brain bleeds, the first accompanied with brain surgery at the Princess Hospital in Hillbrow at an age of months. He underwent this operation before it was known that he was a person with Haemophilia and only received one blood transfusion (not factor) before and one after the operation. Surviving the first brain bleed at four months was a miracle, taking into consideration that Haemophilia was at that stage not yet diagnosed and he received only two blood transfusions! His survival of this ordeal surprised everyone including medical professionals. The first two bleeds were indeed very serious and doctors gave him no chance to live at the time.

With the second brain bleed Jean was in a coma for two weeks without being treated for the bleed because of him having developed inhibitors to factor VIII and no substitute product being available at that time for treating persons with inhibitors. He never the less fought back and lived on to show us all what can be done!

In spite of these and several other setbacks such as knee bleeds and damage, he has managed to achieve remarkable success in his life. He matriculated at the Hope School in Johannesburg in 1992 and obtained a BSc. Honours degree at UNISA in 2003 and his Masters degree in 2005. He obtained a Government bursary for studying for his doctor's degree in Physics on a full time basis at UNISA. He commenced with these studies in 2006 and completed his Thesis by the end of 2009. He was appointed as a junior lecturer at UNISA in January 2010.



Jean de Villiers

We are convinced that God saved Jean for a reason and so we believe it is with every other person with Haemophilia.

In their own way they could all be destined to make a difference somewhere in life. I hope that the determination and fighting spirit which Jean showed in his life, inspire other persons with Haemophilia to do the same to reach their own stars!

From the Editor

In the article "**History of the Foundation** -Where the Foundation came from and what it has become", in a previous issue of the National Newsletter, I referred to a dark period in the history of our Foundation when a number of our members were infected with HIV through the use of infected blood products. This is one event that is not openly discussed between members.

Two of these persons with haemophilia have however had the courage to go public with their HIV status and have been an inspiration to many people with HIV in our society in general. They are the Reverend Christo Greyling and my son, Fanie de Villiers. Both are active in the field of counselling people infected with HIV. I salute them and believe they stand out as examples of people who have turned adversity into opportunity and are serving our community productively!

I am taking the liberty of including an article published by the Eikestadnuus on 25 November 2005 after their reporter, Pertunia Thulo spoke with Fanie. With the permission of Eikestadnuus, this article entitled "HIV does not control me; I control HIV" is repeated exactly as it appeared in the newspaper on page 5 of this newsletter.

Be assured that should you have the courage to write to me about your own HIV tragedy, I

will treat such correspondence as strictly confidential, unless you specifically state that I may share your feelings and experiences with others. Maybe our own experience as a family living with both haemophilia and HIV and those of Christo and Fanie can be of some comfort to those that are carrying the burden alone!

Please address your letters to Albert de Villiers, P.O. Box 631, Hermanus, 7200 and mark the envelope "*Strictly Private and Confidential*".



History of the Haemophilia Foundation

As recalled by Albert de Villiers

The achievements — How far we've come

The Central Region of the Foundation made available the **Arthur Robertson Travelling Fellowship** remembering one of the founding members of the SAHF, Arthur Robertson. As the name suggests, this fellowship was awarded to selected recipients to assist them to travel locally and internationally to further their knowledge of Haemophilia and to stay abreast of national and international developments in the treatment of persons with Haemophilia. Some people who received this Fellowship and who went on to serve not only the people from the Central Region but, also others throughout South Africa, were Sisters Anne Gillham and Anne Cruickshank, Dr. Steven Field who received the Fellowship in 1993 for visiting Haemophilia treatment Centers in the UK. Other recipients of the Fellowship were Fiona Semple, Dr. Rose Schwyzer who all attended various World Haemophilia Congresses and Dr. David Brittain.

The Central Region of the Foundation also made available **study loans** to several of its members to further their studies and in so doing, upheld the mission of the Foundation and assisting the recipients to become independent members of society.

A Sub-committee of the Central Region of the Foundation was formed with the **Baragwanath Hospital** to address the treatment and identification of patients in 1992. This effort was the start of identifying a significant number of new members from the previously disadvantaged community and thus made modern treatment facilities available to them. Similar efforts that successfully identified many of the disadvantaged groups were also initiated in Kwa-Zulu Natal and the Western Cape.

Tom Kessler, the then National Secretary of the Foundation played an important and significant role in and was also the first acting secretary of **the Medically Acquired HIV Institute** (established in March 1993). This was a special trust established to provide financial assistance for persons with Haemophilia who had been exposed to HIV as a result of receiving treatment with infected blood or blood products. Grants, if approved were not intended as compensation for those infected with HIV, but as a humanitarian response to the social problems resulting from the exposure to HIV and Aids.

"... the most important of all the issues addressed by the Foundation was to ensure the continued and affordable availability of treatment for its members."

Perhaps the most important of all the issues addressed by the Foundation was to ensure the **continued and affordable availability of treatment for its members**. In this there were some scary moments. Particularly when the rendering of free medical services for the treatment of chronic health conditions, including Haemophilia was officially discontinued on 1 April 1992. Following this development, discussions took place between the SAHF and the Minister of National Health resulting in the National assembly asking the minister (Dr. Rina Venter) to oversee the development of a national policy for the treatment of Haemophilia. A Working group was established following this event which met in June 1992 to address the issues this had regarding cost and availability of treatment for all chronic conditions in South Africa. Haemophilia, being one of the more expensive conditions to treat, was an important condition that was considered by this working group. Prof. Cyril Karabus and Paul Scott represented the SAHF and their mandate was to ensure the establishment of a national policy for the treatment of Haemophilia patients. Their efforts contributed to the reclassification of patients according to financial means initially and continued treatment was assured albeit at varying costs in various parts of the country. The significance of the contribution of the SAHF in this process cannot be overemphasized. These efforts eventually led to Haemophilia being classified and recognized as a Prescribed Minimum Benefit condition qualifying for free treatment by government and Medical Aid societies not being able to refuse membership or payment in 2003.



Albert de Villiers

During the process that followed the working groups activities mentioned above, a need for a Medical Steering Committee was identified in 1994. The name of the Steering Committee was later changed to the South African Haemophilia Foundation Medical Advisory Committee on Haemophilia. It was initially made up of two medical doctors nominated by each of the Western Cape, Natal, Central, Northern, Free State and Border Regions complimented with two members nominated by the National Council of the SAHF. The purpose of this committee was to be to:

- Formulate and maintain treatment standards nationally;
- Act as the Foundations formal mouthpiece to Government on national treatment standards;
- Ensure that persons with Haemophilia receive equal treatment when visiting other regions;
- Negotiate equal payment arrangements for the treatment of Haemophilia nationally;
- Act as representative body of medical practitioners involved with the treatment of Haemophilia and to present their case on an ongoing basis;
- Report to National Council and the Regions from time to time.

"HIV does not control me, I control HIV"

Eikestadnuus 25 November 2005

Through the years there have been myths and stigma, as well as stereotypes attached to HIV/ Aids. Some people pretend that HIV/ Aids do not exist. However, every year more and more people are infected and affected. **PERTUNIA THULO** spoke to Fanie de Villiers, at the time a Health Promoter at the University of Stellenbosch (US), about how he handles the fact that he is HIV positive.

How do you tell your six-year old boy that he is HIV positive? This was the scenario Fanie de Villiers's parents had to live with until he was old enough to understand that. As De Villiers was born in 1979 with a rare disease of internal bleeding, he is a person with Haemophilia, he had to rely on medication for his treatment. Exactly twenty years ago he became infected with the HIV/Aids virus as result of a blood transfusion. *(Not correct – It was in fact Factor –Ed.)*

He tells his emotionally challenging story as if it happened yesterday and clearly recalls all the events as they occurred. "I am a white guy who has been living with HIV/ Aids for twenty years now. People need to understand that Aids is not a black issue. White people need to bridge the gap and understand that it can happen to anyone. I first heard the news at the age of fifteen. My parents waited for about nine years to tell me I was HIV positive. My life nearly came to a stand still. My first natural reaction which lasted for a long time was a total blow-out. I was furious with my parents, the doctors and also furious with God," De Villiers explained.

"I had an absolute fear of rejection, I started acting rebelliously, and I tried to commit suicide. My attitude towards life was totally negative. I did not want to plan anything and distanced myself from my family."

He was still in high school when he first heard that he is HIV positive. "I remember clearly that it was the most difficult and challenging years

of my life. Eventually after much effort and a great deal of thinking, I went on medication. But I did not want my friends to find out that I am HIV positive." It was not long before he decided to either tell his friends or to stop taking medication because of the side effects that were becoming apparent. "I was vomiting, suffering from continuous headaches, feeling nauseous and dizzy all the time." De Villiers decided not to tell his friends what was wrong with him, but rather to stop taking the medication. "At this stage I did not care what happened to me, because I thought I was going to die the very next day. At the same time I knew I had to open up to someone in order to deal with the issue instead of running away from the problem as I had been doing up to then. I took a bold step and told someone else about my status. For the first time, and since then, I have learnt to take one day at a time. When I decided to go public with my status, I no longer took my personal life into account."

"...people can live a normal life despite their HIV status."

"One of the people that keeps me going is Reverend Christo Greyling. I regard him as my role model. Every time I see him, I am reminded that people can live a normal life despite their HIV status."

"At the age of 21, I went on a tour to Israel with my family. The theme of the tour was 'In the footsteps of Jesus' and that gave me a new perspective on my own life". For De Villiers this was a turning point. On this trip he met someone special and they have been married for three years now. *(Sadly she died very suddenly in 2006 of an unrelated HIV condition – Ed.)*

"People need to realize that there is life after HIV. It does not matter how you got it, carry on with your life. It

takes so much from a person, but you need to be strong. HIV does not control me, I am in control." De Villiers said that at times it becomes difficult for him, but his wife is always there for spiritual support and that keeps him going forward. *(This last sentence as it was then – see note above – Ed.)*

God is my pillar of strength. It is important to have people around you that can support and help you in times of need. Being able to manage yourself is important. If you can do that, you can begin to help other people in the same situation."

ADVOCACY WORKSHOP 4-7 JUNE 2009:

The fight to secure treatment for people with bleeding disorders in Africa exists alongside many other healthcare challenges. SAHF hosted the WFH's African Advocacy Initiative conference in Cape Town at which Haemophilia patient organisation delegates from all over Africa met together to participate in workshops designed to help foster advocacy campaigns in their own country. 17 delegates from 12 African countries attended and the workshop was led by Mark Skinner, President of WFH, together with members of the WFH Executive. Bradley Rayner and Prof Johnny Mahlangu participated as facilitators, Albert Ngombela and Patrick Diedricks from Johannesburg were SA delegates and Khulekani Chonco (KZN) and Dennis Kiburu (E London) were observers.



CULTURE vs CONDITION

Obstacles facing a Haemophilia Nurse

By Henry Steenkamp

According to the Xhosa culture, 19 year old Nkosinathi*, is now a man. He is one of the many people with Haemophilia (PWH) who preferred to be circumcised in the traditional way as opposed to having the procedure done in a hospital. Due to the great support provided by Mr Henry "Steenie" Steenkamp (Frere Hospital Haemophilia Nurse) and Mr Mkiva (Circumcision Co-ordinator) towards Nkosinathi, he was able to undergo a safe and successful circumcision on 9 December 2009 in Cofinvaba in the old Transkei.

It all started in November 2009 when Mr Steenkamp received an e-mail from Sr Anne-Louise Cruickshank informing him of Nkosinathi's intention to undergo a traditional circumcision. Upon checking the Haemophilia register Mr Steenkamp realized that Nkosinathi was not known to Frere Hospital's Haemophilia clinic. Viral screens and inhibitor testing were last done in the 1990s.

Mr Steenkamp informed Mr Mkiva about this boy, with factor IX deficiency, who wanted to undergo a traditional circumcision and Mr Mkiva then attended to the matter promptly and efficiently.

On 25 November 2009 Mr Steenkamp cut short his annual leave to attend to Nkosinathi at Frere Hospital, due to the fact that there were no senior staff capable of processing a new haemophilia case. Without delay Mr Steenkamp proceeded to do the necessary tests i.e. inhibitor testing, viral testing etc. There was an unforeseen delay in the inhibitor test which almost drove Nkosinathi's mother to take him to the Initiation School before all the results were available, but through proper explanation by Mr Steenkamp on the importance of the results, he was able to convince her to postpone the circumcision of her son.

After collecting factor IX from the Frere Hospital Blood Bank, Mr Steenkamp and Mr Mkiva left for Cofinvaba at 2 am on 9 December 2009. Nkosinathi was circumcised under the supervision of Mr Mkiva after he received 300 IU of factor IX pre-circumcision. On return to the camp to give Nkosinathi his second dose of factor IX, a heavy downpour prevented them from reaching the camp. The small stream was turned into a raging river. Mr Steenkamp phoned Sr Cruickshank to inform her about their predicament as this

meant that Nkosinathi would not be able to receive his second dose of factor IX. Sr Cruickshank felt that due to the unfortunate circumstances they should omit the second dose altogether. On returning to the vehicle the team felt that they should try everything to find a way to administer the second dose to Nkosinathi. Luckily they found a safe area (big rocks) to cross the river about one kilometer up stream. Once back at the camp site they proceeded to administer Nkosinathi's second dose of factor IX. Mr Mkiva and Mr Steenkamp spent five days in the Cofinvaba area administering factor IX to Nkosinathi.

As a matter of interest it was noted by Mr Steenkamp that Nkosinathi's circumcision wound was healing faster than the other initiates – as was also noted with a previous PWH initiate who was treated by Thembilani and Mr Mkiva in December 2008.

* name changed to protect patient's identity

Mr Steenkamp & Mr Mkiva wish to thank the following:

- ✦ Frere Hospital transport department
- ✦ Frontier hospital for accommodation
- ✦ National Bioproducts Institute
- ✦ Frere Hospital Blood Bank
- ✦ Managers at special clinic at Frere Hospital for allowing their staff to attend the initiation
- ✦ Their families for their patience
- ✦ Sr Cruickshank, Dr Knox and Dr McDonald



Pre-circumcision factor IX administration in conditions well beyond the norm.



Mr Henry Steenkamp with the life saving factor IX.



Boulders & rocks that had to be used as leverage, to cross the fast flowing river after the storm.

* Photographs courtesy of Henry Steenkamp

A Journey of Learning and Discovery

The South Africa—Canada twinning initiative 2005 - 2009

By Bradley Rayner, Chairman of the South African Haemophilia Foundation

The four year twinning between the Canadian Hemophilia Society (CHS) and the SA Haemophilia Foundation came to an end in December 2009. One of the highlights was winning the World Federation of Hemophilia (WFH) Twins of the Year award for 2008. This award was presented to Bradley Rayner, Chairman of SAHF, and Pam Wilton, President of CHS, by the President of WFH, Mark Skinner, at a ceremony at the Charlotte Maxeke hospital during the visit of WFH to South Africa in June 2009.

"Our Twinning partnership with the CHS has been a journey of collective discovery"



(Left to right) Mark Skinner (WFH), Bradley Rayner (SAHF), Ms Pule (Chief Matron), Pam Wilton (CHS), Dr Mfenyane (CEO) and Eric Stolte (CHS).

During the four years of the twinning, members of the SAHF visited Canada and delegations from the CHS visited SA on 3 separate occasions. The first visit by CHS was an exploratory one for the Canadians to experience the challenges faced by SAHF and to hear first hand from the people in the different regions. In 2007 they again visited to assist SAHF in a Strategic Planning symposium in Johannesburg and the third visit in 2009 was for an updating of the SAHF Strategic Plan as well as to attend the World Federation of Hemophilia Advocacy workshop which took place in Cape Town in June 2009. (see article p 5).

"Our Twinning partnership with the CHS has been a journey of collective discovery," said Bradley. "It was very important for our organization to identify initiatives and activities, suggested by the CHS, that can be adapted and that we can take ownership of here in South Africa, to improve care and the SAHF as an organization based on CHS experience and lessons." We understood what has worked for Canada could not be applied to the South African context verbatim. Numerous socio-economic challenges have an impact on achieving the SAHF objectives. Our expectation was not one of a "quick fix", but a journey of "learning and discovery", sharing ideas with a strategic objective in mind.

SAHF was fortunate to obtain funding as part of the twinning process from the WFH as well as from the CHS themselves. With this assistance and additional funding SAHF raised, SAHF was able to fund 60 delegates from all over SA to the Strategic Planning meeting in 2007. The Strategic Plan was reviewed and updated in 2009 by representatives from the regions and members of CHS.

As part of the Twinning process Wayne Fowles, Chairman of KZN branch, attended a Youth camp in Canada in 2008 funded by CHS. He used the knowledge and experience he gained to facilitate a very successful camp for PWH in Durban in December 2009 (see report on p 1).

The twinning provided momentum, focus and pressure which delivered results. Further work is required with consistent pressure to further the aims of the SAHF. The SAHF will endeavour to assist other African countries and share their newfound knowledge and skills having been through such a strategic twinning of organisations.





**P.O. Box 172
Plumstead
7801**

**Telephone: 021 785 7140
E-mail: butlersr@iafrica.com**

We're on the Web

<http://www.haemophilia.org.za>

Contact People

**Bradley Rayner
National Chairman**

Cell: 082 882 6420
E-mail: bradley.rayner@za.didata.com

**Judy Butler
Operations Manager**

Phone: 021 785 7140
Cell: 083 711 7287
E-mail: butlersr@iafrica.com

Nurse Counsellors

**Cape Town
Sr Anne-Louise Cruickshank**

Cell: 082 7881038
E-mail: anne-louise.cruickshank@uct.ac.za

**Central region
Brian Allingham
Regional Chairman**

Phone: 011 372 9940
Cell: 082 492 3202
E-mail: ballingham@tyco-valves.com

**Pretoria
Marchaine Wright**

Cell: 082 41 88417

**Eastern Cape
Richard Johnson**

Phone: 041 583 3159
Dennis Kibiru
Phone: 079 555 7271

**Johannesburg
Sr Anne Gillham**
Cell: 083 225 9850
E-mail: Anne.Gillham@nbisa.org.za

Regional Contacts

**KwaZulu-Natal
Wayne Fowles
Regional Chairman**

Cell: 082 321 0931
E-mail: wayne@fotomax.co.za

**Limpopo
Culphus Rikhoto**

Cell: 0734155668
David Mogamisi
Cell: 0734806385

**Free State
Mlungizi Ningiza**

Cell: 083 351 6020
Phillip Shapu
Cell: 078 331 0744

**Johannesburg
Sr Alice Banze**
Cell: 082 896 3833
E-mail: alice@haemophilia.org.za



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