



## **SAHF HAEMOPHILIA FOUNDATION CHAIRMAN'S REPORT - November 2007**

This report covers the period from November 2006 through to November 2007. The past year has been even busier than previous years with many activities successfully completed for people with Haemophilia (PWH) and the community it serves. The SAHF is an important organisation to the improvement and development of care for PWH in Africa and SA. **TREATMENT FOR ALL! STOP THE BLEEDING!**

The organization has grown and continues to grow in many respects. This growth is attributed to the commitment and dedication of a few volunteers. However it has put further demands on the current volunteer base time. The SAHF requires new volunteers to participate by committing a few hours a month to assist the SAHF in meeting its stated goals and objectives. It is important to note that long serving members are tiring and require the assistance of new volunteers with new and fresh ideas to evolve the organization to address the challenges of changing times for the benefit of all PWH.

A Strategic Plan was drafted based on a process of questionnaires and a nationally, well represented 3 day workshop event in Johannesburg attended by 60 diverse participants. Four key objectives were identified; viz; Organisational Development, Advocacy, RURAL and Treatment. The twinning initiative with the Canadian Haemophilia Society and the assistance of the WFH continues to provide valuable support to the SAHF. Further to this we continue to broaden the SAHF through the establishment of additional ROCK groups (Reach Out Centre for Kids). This programme takes the “point of presence” of the academic hospitals (treatment centres) into the local communities, improving service delivery and access of treatment for PWH. Building onto this the SAHF has an intention to form a regional committee in the Western Cape from the ROCK co-ordinators to meet the stated strategic goals.

The organisation continues to make a difference with the limited resources and volunteers at its disposal. Haemophilia has been moved from the Maternal Health directorate to the Chronic disease Directorate in the WC. This will create new challenges and opportunities for the Haemophilia Foundation.

A summary of activities and achievements are listed:

1. Annual camping weekend in conjunction with “Reach for a Dream”.
2. Meeting with the Canadian High Commission to advocate for PWH.
3. Teleconferences with the Canadian Haemophilia society and the World Federation of Haemophilia
4. Nurses training including nurses from other African countries to build capacity to serve PWH.
5. 17<sup>th</sup> April, World Haemophilia day awareness programmes on radio and a media brief to newspapers
6. Various talks and training to the broader medical community to improve knowledge on Haemophilia.
7. Alert de Villiers agreed to be the editor for the National Newsletters for 2008.
8. The WCHF has employed the services of an Operations Manager, Judy Butler to replace Abigail as she took up another job offer. Judy responsibilities are to improve the operational activities of the foundation and to fundraise. The Strategic Planning event was a great success because of Judy’s organizational efforts. The Haemophilia communities continue to enjoy the benefits of this post.
9. Assistance to financial resources for needy persons of the Haemophilia community for education, transport, clothes, food and application for government grants etc.
10. Negotiation for continuous sponsorship for full-time posts for our nurses. This funding greatly benefits all the Haemophilia community especially the outreach.
11. Working with Nova Nordisk to develop a programme for World Haemophilia Month in April 2008 utilising the NN bus around SA.
12. Developing a job specification to perform the responsibility of National ROCK co-ordinator.



These achievements have been accomplished by a few dedicated volunteers. The SAHF is struggling to attract new or young members interested in assisting the Foundation. Members could assist by writing articles for newsletters or web site, assist with fund raising, media liaison, general tasks or activities. If you are interested in assisting or getting involved, speak with any of the committee members. Quality of treatment received for PWH can be improved by focusing effort directly towards the treatment centers that service your needs or the communities within the area.

**WE CONTINUE TO HAVE DEATHS OF KNOWN HAEMOPHILIACS BECAUSE OF IGNORANCE AND LACK OF TREATMENT. TAKE RESPONSIBILITY FOR YOUR CHILD OR YOUR OWN HEALTH. EACH BLEED CAUSES DAMAGE AND COULD PROVE FATAL WHEN IT IS SERIOUS AND NOT TREATED!**

Through TCPiD; viz, **T**eam work, **C**ommunication, **P**ersonal involvement and **D**edication we can improve health care for ourselves and people with bleeding disorders.

Budget constraints continue to be a problem in providing the best care that the Haemophilia Foundation advocates. Patients who have inhibitors rarely get the treatment required. We continue to advocate for all PWH by writing letters and meeting with the Department of Health. We need your support, assistance and involvement to create a strong foundation to assist the committee to lobby government for improvement to the health system service delivery.

Funding is essential for our cause and we ask anyone that can obtain corporate social investment or any other form of sponsorship to assist the foundation. Christmas cards and calendars are on sale.

We acknowledge the commitment and dedication of the various committees and look forward to new volunteers who will avail themselves to assist with fresh ideas and energy. I extend our greatest appreciation and gratitude to doctors, nurses, caregivers other interested parties which includes the DOH and sponsors that assist in providing and improving health care for the Haemophilia community.

On behalf of the committee(s) I wish you all the best for the New Year.

Bradley Rayner  
Chairman South African Haemophilia Foundation

A handwritten signature in blue ink, appearing to read 'Bradley Rayner'.