The December 2005 issue of Hemophilia Today reported on the newly formed twinning between the South Africa Haemophilia Foundation (SAHF) and the Canadian Hemophilia Society. Since then representatives of the SAHF have visited Canada to attend the CHS strategic planning event in Toronto in February and see the CHS in action at national, provincial and regional levels. Hemophilia Today asked the SAHF President to tell us about the twinning from his perspective.

**Bradley Rayner**
President, South Africa Haemophilia Foundation

Hemophilia in South Africa (SA) is like an expensive car and a donkey cart traveling on the same highway. If you have access to treatment centres that have clotting factor, your journey is generally smooth… provided you do not need the expensive inhibitor products. Should you, however, live in rural areas you travel the bumpy road of pain, crippling and even death. In South Africa people with limited access to financial resources who live in the rural areas have the added challenge of getting to the closest treatment centre. Unfortunately, travel delays have resulted in several cases of severe hemorrhaging ending in death. In the rest of Africa the situation is much worse because of the lack of treatment products and treatment centres.

In November 2003, in discussions with Dr. Assad Haffar, World Federation of Hemophilia (WFH) Program Officer for Africa, it became clear that the SAHF had the opportunity to improve and offer its expertise in the Southern African Region. But like any successful organization looking to expand we had to be successful in our own country, especially improving local regional committees (chapters).

An acronym that probably best describes what we need to do is to apply the principle of TCPiD; that is, Team work, Communication, Personal involvement and Dedication, so that we can improve health care for people with bleeding disorders.

The South African Department of Health has huge challenges to meet its responsibilities for all people in South Africa. Illnesses like tuberculosis and HIV affect a large percentage of the population and are prioritized above haemophilia. Access to inhibitor treatment is a problem. A treatment programme for hepatitis is not readily available because of budget constraints. Socio-economic issues impact access to treatment and quality of life.

**Benefits of twinning**

We decided that we needed executive assistance to assist the SAHF strategically and to formulate a plan to set a path going forward. We needed a partner that was experienced, established, and could advise the SAHF on lessons learned, specifically as regards national and regional government structures and geographical challenges similar to our own.

We believe that an organization like the Canadian Hemophilia Society (CHS) is closest to the ideal partner. The CHS has matured through various phases and can assist the SAHF in many initiatives: defining a strategic plan, assisting the SAHF with educational material and literature that the CHS has available and that the SAHF would find extremely difficult to compile, sharing experiences in areas of common strategic importance, expanding networks and reaching out, sharing resources and gaining access to contacts depending on the need, and changing people’s lives for the better.

**Challenges of twinning**

We understand what has worked for Canada cannot be applied to the South African context verbatim. Numerous socio-economic challenges have an impact on achieving the SAHF objectives.

Our expectation is not one of a “quick fix”, but a “journey of learning and discovery”, sharing ideas and always looking for “quick wins” with a strategic objective in mind.

The main challenge to achieving our objectives is having the participation and volunteer base that represents all the stakeholders to assist with the project. Fund-raising is critical to financing the activities and hosting the event. Since the SAHF has no paid staff, we must make time as per our schedule and tasks identified.

We are positively inspired by the visit with the CHS in Canada and grateful for the chance to participate in the strategic planning session. The Canadian hospitality was warm and the people genuinely interested. The SAHF is grateful for this opportunity created by the CHS and WFH. We look forward to making a difference!