Pam Wilton, R.N.
Vice-President, Canadian Hemophilia Society

“Are we there yet?” the man across the aisle asked.
I laughed and shook my head, “No, but we’re getting closer.”

That was the first sentence I had spoken since we left Atlanta eight hours earlier. I seemed to be the only person traveling alone in our part of the cabin and I was grateful for some conversation. We had just landed on the Island of Sol, a little dot in the Atlantic Ocean, off the coast of Senegal. The man told me that he was hunting “big game” and assured me that he would be able to keep up with his hunting buddies, despite his fractured ankle. I nodded and said a silent prayer for the animals.

I told him that I was a volunteer, headed to South Africa, where I would meet up with Stéphane Bordeleau, Executive Director of the CHS, and Eric Stolte, our President, to determine how we could work together with our new twin, the South African Hemophilia Foundation, to improve the lives of people with bleeding disorders.

Eight hours later our plane landed in Johannesburg where I transferred to a final flight into Cape Town. South Africa was even more beautiful than I imagined! It is about a tenth the size of Canada, with a population of about 43 million. There are 11 official languages, with cultural traditions different from ours. Most were adequately equipped and the level of staffing, human resources, extremely dedicated but limited in common: long distances between cities, asking lots of questions. We learned that the CHS and the SAHF have many things in common: long distances between cities, language barriers, limited financial resources, extremely dedicated but limited human resources, an abundance of work to be done, dedicated medical teams, highly skilled volunteers and, of course, a common vision.

Over the next 6 days, we visited 6 cities and 7 clinics. We participated in 3 workshops with members from the SA hemophilia community. We also met with the administrators from several hospital sites.

In many respects, clinics were not much different from ours. Most were adequately equipped and the level of staffing, including allied health, seemed similar. We were fortunate that staff took time to meet with us to answer questions, identify challenges and share thoughts. South African doctors and nurses are very well trained, but, as in Canada, there is a shortage. They have also experienced a “brain drain”. There is a two-tiered system. Those who are employed usually have insurance and unlimited access to care and factor product. Those with no insurance receive care at the public hospitals, where they have access to factor concentrates, but the factor is rationed. It seemed that individual administrators often make decisions about treatment. It was actually quite disconcerting to hear the nurses plead with the administrator in one hospital to approve additional treatment for a young man with an inhibitor, saying that he is a university student, studying hard and hoping to find employment. It was also startling to meet representatives from the pharmaceutical companies, who provide the factor, not only present in the treatment areas of the clinic but often assisting with hands-on care. One other interesting problem is that those who have insurance often have access to product as needed, but not necessarily hemophilia expertise, because their insurer dictates where they must receive care. In each clinic we met hemophilia nurses, called Sisters, who work endless hours providing their expertise and skill to help meet the needs of those they serve. They are also driving most of the SAHF work. These are truly amazing women. We met dedicated and overworked physicians. And we met physiotherapists with excellent skills who know how to do a lot with a little!

continued on page 32
We were privileged to meet many patients who allowed us to visit with them in both outpatient and inpatient areas. We learned that the children who have regular access to care and treatment are doing very well and that the older guys have the same problems as Canadian men: joint deformity, disability, pain and HIV/AIDS. In the smaller centres, such as Polokwane, we met parents who had lost sons because of a lack of knowledge and access to care.

We also met youth who had traveled many miles to speak with us, most often at great cost to their families as extremely limited resources were used for bus fare. Many of those same boys are capable of home infusion, but do not have refrigeration facilities, nor are they able to pick up factor from their hospital if they have an unpaid user fee on record.

During workshops, volunteers were asked to identify strengths and weaknesses of the SAHF, as well as areas with which they thought the Foundation could help. As is the case in Canada, we met lots of skilled volunteers who have great potential to help the SAHF grow and prosper. We met experienced leaders who are willing to mentor potential future leaders.

One afternoon, one of the Sisters took us to one of the settlements to meet a young shoemaker who has severe hemophilia. The man met us in his wheelchair at the entrance to his tiny workshop, adjacent to his home. He had been involved in some sort of violence and been stabbed in the back. He bled into his spine and is now hemiplegic. He showed us the sewing machine the SAHF purchased for him and spoke of his plans to get a booth close to a local shopping area where he would have more chance for walk-in business. The sun was getting low in the sky on that spring day in Africa. A few hours earlier, I had stood at the site of the world’s first human heart transplant and now I stood in the muck, just a few miles away, on the edge of Cape Town and I saw dignity and hope in that man’s eyes. The SAHF gave him that with a used sewing machine.

On our final day together, Bradley and the leaders from the SAHF met the three of us to debrief and to begin to develop an action plan. We see huge potential for the two countries to work together to achieve our goals. Stéphane, Eric and I have developed a draft action plan. Once the plan has been approved by the SAHF and the World Federation of Hemophilia, we will be able to move forward. One of the first tasks is to help South Africa develop a strategic plan. We have much to learn from the South Africans, too. Bradley called our work together, “a journey of learning” and on that last day in South Africa, after an experience which Stéphane best summed up as “intense and fascinating”, Eric presented Bradley with a small Inukshuk. Inuit use the Inukshuk as a directional marker, signifying safety, hope and friendship.

So… are we there yet? No, but we’re getting closer.

World Federation of Hemophilia
4th Global Forum on Safety and Supply

Marius Foltea
CHSQ Board of Directors

On September 26-27, I had the opportunity to attend the World Federation of Hemophilia’s (WFH) Fourth Global Forum on the Safety and Supply of Treatments for Bleeding Disorders that took place in Montreal. During this meeting, where 150 researchers, doctors, blood system operators, regulators, pharmaceutical representatives and patients from around the world gathered, many themes were dealt with, including:

• Research into new products and new fractionation processes
• The WFH humanitarian donation program
• The Canadian project for the recovery of factor VIII from Canadian plasma
• The incidence of inhibitors
• Access to therapies for rare bleeding disorders (other than hemophilia A & B)
• Approaches of various countries for soliciting tenders and choosing therapeutic products
• The possibility of a variable price structure to facilitate access to factor concentrates in developing countries
• Safe treatment.

Several presentations were made by those responsible for the regulation of blood products. The conclusion was that expiration dates must be respected, even when products are donated for humanitarian aid, and even though it is known that products retain their efficacy long after the expiration date. A recommendation was also made that viral testing is useless on an end product since there is no test recognized for this purpose. Safety is solely dependant on donor selection procedures, virus detection in donations and good manufacturing practices, including viral reduction, during the production stages.

One doctor presented part of his research on factor VIII dosage. According to him, a dose smaller than that to which we are accustomed in Canada may be just as efficient. But there are many unanswered questions on this subject and research is ongoing. What’s more, many doctors doing research on the incidence of inhibitors lack data (the number of inhibitors or patients registered in the study is too low) to come to valid conclusions as to the association with a specific product, for example, recombinant factors. This led to a number of heated discussions between specialists.

The following items in particular caught my attention:

• 88% of recombinant products are used in North America and Europe (especially in the richer countries).
• Around the world, there is a great quantity of plasma that isn’t used for the production of factor concentrates and is, for all practical purposes, wasted. Many countries could benefit from this product. However, technical, legal and ethical questions have to be dealt with before this can happen.
• A number of countries are thinking about building their own plants to produce plasma-derived products in an attempt to minimize the cost.
• The way to identify the number of units on bottles of concentrates required by authorities is not consistent in Europe in comparison to North America (approximate amount versus exact calculation). This entails supplementary costs when products are exported from one continent to the other.
• The cost of the same therapeutic product is not consistent from one country to another.

I’d like to thank the CHSQ for giving me the opportunity to attend this very interesting forum. If you’d like to know more about it, you can consult the WFH website at www.wfh.org.