speeches, and then we answered the audience’s questions. The atmosphere was very friendly and we had a lot of fun.

Our first trip was focused on organizational structure and by-laws. The IHS had some deficiencies in their constitution and we were able to assist them to make some changes by adapting some of the by-laws of the CHS and Hemophilia Ontario constitutions. Shortly after, they came up with a new constitution which has more democratic features and gives more power and freedom to the chapters and members. IHS has now grown to 21 chapters. IHS also publishes a quarterly journal called “Life” which has all the information that people affected with bleeding disorders need to know. This is another example of the teamwork of Shirin, Ali and Ghavidel.

A few days later we went to Mahmoud Abad on the Caspian Sea coast to attend the Regional Hemophilia Seminar. This conference was organized by Dr. Ala and the IHS office with some help from the CHS. Attendees included the teachers of the local primary schools to help them understand more about bleeding disorders. It was an excellent opportunity to educate the local people about the importance of proper and timely treatment for hemophilia.

The new Comprehensive Hemophilia Care Centre in Tehran has up-to-date technology including supplies for the coagulation and genetics lab, purchased with charitable donations from inside and outside of Iran. The clinic also established dentistry and orthopedic clinics specializing in hemophilia. The clinic also started a new registry of people with hemophilia.

Ariyan, the talented 14-year-old son of Shirin and Ali, established a computer networking system in the clinic which records detailed information about the patients, their history and even their x-rays.

For me, who had been out of the country for 12 years, this clinic is a great achievement.

2003 Visit to Iran

On our first twinning visit Barbara Peters and I visited the IHS office and staff who seemed to be very organized and dedicated. Mr. Ghavidel, the Executive Director of the IHS, gave us a tour of the three-story building. The third floor has been converted to a dormitory for people who travel from remote cities to Tehran to receive hemophilia treatment.

Ghavidel is a highly motivated man who put a lot of effort into getting media attention to uncover the Iranian blood scandal. Having a child with hemophilia, Ghavidel had an in-depth understanding of the issues. He is the man whose face and voice were on the front page of newspapers and on TV in the days when the blood scandal was the hot topic of the country. He endangered his own life by calling for justice when it became clear that authorities of the Iranian Blood Organization had failed to test products purchased from France in the late 1980s. His efforts eventually paid off and the issue of the contaminated factors was brought to a court of justice. The affected patients received compensation plus free treatment for HIV and hepatitis. A number of authorities received short or long term jail sentences. For the first time in the judicial history of Iran, patients’ rights regarding viral infections were respected.

In our tour of the IHS office, Barbara and I were stunned to see a great number of wives or family members of people with bleeding disorders volunteering at the office. We won’t forget their warm reception, particularly the famous Iranian chelo kabab which was served for lunch. Ghavidel, Barbara and I made some short speeches, and then we answered the audience’s questions. The atmosphere was very friendly and we had a lot of fun.

Our first trip was focused on organizational structure and by-laws. The IHS had some deficiencies in their constitution and we were able to assist them to make some changes by adapting some of the by-laws of the CHS and Hemophilia Ontario constitutions. Shortly after, they came up with a new constitution which has more democratic features and gives more power and freedom to the chapters and members. IHS has now grown to 21 chapters. IHS also publishes a quarterly journal called “Life” which has all the information that people affected with bleeding disorders need to know. This is another example of the teamwork of Shirin, Ali and Ghavidel.

A few days later we went to Mahmoud Abad on the Caspian Sea coast to attend the Regional Hemophilia Seminar. This conference was organized by Dr. Ala and the IHS office with some help from the
Mazandaran chapter. Delegates were mainly representatives of Middle Eastern countries. They got together to discuss regional issues as well as to upgrade their understanding of the treatment of bleeding disorders. I saw some famous scientific faces there such as Dr. Christine Lee and Dr. Carol Kasper.

Visit to Canada

Ali Tchupan, the president of IHS, came to Toronto in January 2005 and a meeting was held at Hemophilia Ontario. Future plans were made including constitutional amendments. Tchupan also visited the hemophilia clinic at the Hospital for Sick Children.

2005 visit to Iran

I traveled to Iran alone in September 2005. This time my main focus was on local chapters. I wanted to hear the chapters’ issues and concerns directly. The first chapter I visited was Isfahan. Assad Haffar, WFH Program Officer for the region, joined me. We received a warm reception from the board members, Mr. Naghashian and Mr. Karami. We also had the opportunity to visit the hemophilia clinic, volunteers, members and staff of the Isfahan chapter. We paid a visit to the Isfahan branch of the Iranian Blood Organization which seemed well equipped.

One thing which astonished me was the idea of Naghashian and Karami to do job creation for people with hemophilia by establishing a factory in Isfahan. In this factory people with hemophilia are assigned light or heavy jobs according to their disability level. This is a great achievement in terms of job creation for people who were considered a burden on society.

On this visit Assad and I gave some input to the Isfahan Chapter on its bylaws, relations with IHS and the ways they can work more efficiently with each other.

In summary, I think within a couple of years we have achieved a lot with regard to twinning with Iran, notably significant amendments to their constitution. Although some other projects such as creating pen pals have failed so far, I will continue to examine new avenues to upgrade our relationship.

The Global Perspective

Twinning can provide unexpected results

Sue Feere, Central Western Ontario Region (CWOR)

The twinning partnership between the Central Western Ontario Region (CWOR) and Serbia has shown some wonderful and unexpected results since its inception in 2004. The most recent activities included meetings and presentations at the 2006 World Congress in Vancouver and a CWOR twinning visit to Serbia.

The International Projects Committee of the Canadian Hemophilia Society sponsored attendance at the World Congress. The opportunity to meet with not only the Society twins but also with the medical twins helps to solidify and streamline efforts on all sides. It also provided the opportunity to attend numerous presentations and symposia on many topics related to bleeding disorders.

At the World Congress in Vancouver, one of the twinning representatives from Serbia, Dejan Krstic, prepared and presented on the topic HIV/HCV, A Serbian Perspective. He was able to speak publicly about some of the personal challenges he faces living as a co-infected severe hemophilic in Serbia.

This was monumental for him on several levels. Serbia has a culture that discourages public discussion that one has hemophilia, let alone is infected with HIV or HCV. Indeed, the twinning between our two societies has been the catalyst for this open discussion. It began at our assessment visit in 2004 where in hushed tones he privately admitted his medical status. When he realized that he could discuss this without repercussion, he sought the opportunity to discuss HIV and HCV.

Then during the Serbian visit to CWOR, we were pleasantly surprised at the openness with which he was able to discuss his medical issues. Dejan felt comfortable to share his ongoing challenges with many of the hemophiliacs and Society members he met in Canada.

This has evolved to presenting in public for the first time in Vancouver. Not only was this his first experience at presenting a PowerPoint presentation, but he did so to sixty Congress attendees. Never mind that the presentation was in English, not his native language; never mind that the PowerPoint presentation was the first he had ever prepared; never mind that he was nervous and couldn’t sleep the night before: the presentation was an overwhelming success. The session chair observed that you could have heard a pin drop during his talk. The audience was so moved by his “from the heart” experiences that there was a standing ovation.

To express my pride in him is an understatement. The courage to come this far, I believe, would not have been possible without the support of the twinning project. These unexpected results should make us all feel honoured to be part of the twinning initiatives and encourage us to continue to support these relationships.

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