The challenges to developing hemophilia care in China are colossal. With a population of 1.3 billion, China is estimated to have about 65,000 to 100,000 people with hemophilia (PWH).

While there are well-trained hematologists interested in the care of these patients, the problems they face include: insufficient infrastructure and the high cost of treatment products. Thus only a fraction of the patients have been diagnosed and hemophilia care is poorly developed. In 2004, the National Hemophilia Registry at Tianjin, reported 4132 PWH registered at 11 clinics, suggesting that only about 5% of PWH are accessing hospital care. Most PWH suffer severe joint disabilities with poor quality of life and a shorter life expectancy.

The Canadian Hemophilia Society (CHS) first became involved with hemophilia care in China in 1993, supporting Dr. Poon to travel to a World Federation of Hemophilia (WFH) workshop in Tianjin. CHS also encouraged the establishment of the WFH twinning between Tianjin (Hematology Institute) and Calgary (Dr. Poon) in 1997. In 2000, WFH launched a priority project for China. Two twinning partnerships were added: Guangzhou (Nanfang Hospital) with Ottawa (Dr. Luke) in 2000, and Shanghai (Ruijin Hospital) with Calgary and Ottawa in 2002.

With grant funding from WFH and CHS, four educational booklets were published in Chinese. Peter Jones’ Living with Haemophilia was translated. A team of professionals was trained in Canada, U.K. and Singapore. Five patient leaders were trained by WFH and CHS and they are most effective in their roles within their communities, establishing a web base, Hemophilia Home of China. Between 2001-05, WFH launched four official visits to China.

In 2001, at a priority setting conference in Guangzhou, three priority projects—registry, nursing and diagnosis—were launched. The development of a National Hemophilia Treatment Centre Collaborative Network to coordinate future development was planned. This was inaugurated at the WFH Hemophilia Conference (Jinan) in March, 2004, with six founding centres from Beijing, Tianjin, Jinan, Heifi, Shanghai and Guangzhou.

The major predicaments facing PWH are access to care, high cost of treatment and lack of services for joint disabilities. Our next strategies will focus on improving care to a large number of PWH by addressing these issues. Our priorities are to promote home care for hemophilia, and to develop hemophilia nursing and physiotherapy, essential services not presently available. In addition to training initiatives, we will develop a hemophilia nursing manual appropriate for use in China and a physiotherapeutic exercise guide for home use. A Bayer International Award for 2005 has been granted for the nursing project.

At the regional level, we started developing outreach networks. In 2004, in Beijing, a consortium of four hospitals was established to coordinate hemophilia care. In Guangzhou, a WFH grant was awarded to develop a clinical network with four regional hospitals.

China is perhaps an ideal place to determine minimal effective therapeutic factor dose, as concentrates are not affordable. Minimal dose prophylaxis to protect children from joint damage is an urgent need in China.

We appreciate the continued support from our partners, CHS, WFH and other stakeholders. At present with the firm commitment of the National Hemophilia Treatment Centre Collaborative Network, we have a great opportunity to move hemophilia care forward in China.