THE IRANIAN HEMOPHILIA SOCIETY AND HEMOPHILIA ONTARIO

The history of care in Iran

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This is the first in a two-part series on hemophilia in Iran. This installment looks at the history of hemophilia care in that country. The second part, to be published in the summer issue of Hemophilia Today, will examine the current situation and the goals and activities of the Iranian Hemophilia Society and Hemophilia Ontario twinning.

Until the mid 1960s there was no laboratory diagnosis of hemophilia in Iran; the physician used his best clinical judgment. In 1966 the first rudimentary diagnostic lab for the diagnosis of bleeding disorders was established at Tehran General Hospital. At that time the treatment was mainly with cryoprecipitate. There was no viable hemophilia society.

In the late 1960s the first hemophilia clinic was established at Tehran General Hospital by two dedicated physicians, Dr. Ala and Dr. Shoaei. These were two physicians who diagnosed my own hemophilia in 1970 and I remember before that no other doctor was able to give my mother a definitive answer about my joint swelling and bleeding tendency. With their efforts the first physiotherapy centre exclusively for people with hemophilia was established in 1971 at the Tehran General Hospital.

In the late 1970s some parents of PWH met at the clinic and decided to establish a society. This very first step was similar to what happened years before at the kitchen table of Joyce Rosenthal here in Canada. The society gradually grew but did not have much power until in the 1990s Shirin Ravanbod and her husband Ali Tchupan made great efforts to make the Iranian Hemophilia Society world class.

In the late 1960s Dr. Ala not only established the first hemophilia clinic in Tehran, but he also became the founder and director of the first Iranian Blood Organization. Before that donated blood was mainly stored in blood banks without appropriate processing to separate the coagulation factors from the blood.

In 1971 with the efforts of Dr. Ala, the World Federation of Hemophilia (WFH) held its 7th international congress in Iran. This was a great achievement for Iran. Hemophilia conference coverage in the media created significant public and physician awareness. The existence of a therapeutic centre in Tehran became known. The centre began to get referrals from the small cities.

Hemophilia care was taking great steps until the revolution of 1979. The political and social instability in the country after the revolution was a major setback to the growth of hemophilia care in Iran. The social and political pressures caused many educated people to leave. Dr. Ala moved to England and later became the head of Birmingham Blood Agency; Dr. Shoaei chose France to live and work.

Hemophilia care continued to deteriorate for years after the revolution without anyone’s voice being heard. In the late 1980s the importation of contaminated blood products added to the crisis. However this acted as a trigger for PWH and their families to raise their voices and be heard by the society and the government. In the mid 1990s more attention was gradually given by the government to rare diseases such as hemophilia and thalassemia. A special budget was allocated but still there was no world class clinic. The families of people with hemophilia, in particular Ali Tchupan and Shirin Ravanbod, called for Dr. Ala’s help.

Dr. Fereydoun Ala, a highly dedicated and compassionate physician, responded to their call and accepted to return to Iran to establish a world class Comprehensive Hemophilia Clinic. As Dr. Ala said, “It was the power of love which brought me back to the country again.”

He then established a world class comprehensive hemophilia clinic with non-governmental funding, mainly from donations. Ali and Shirin bought an abandoned building in Tehran and renovated it. This painstaking work took a great deal of their time but eventually paid off. With the volunteer work of Dr. Ala, a state-of-the-art Comprehensive Hemophilia Clinic with dedicated personnel, including doctors, nurses, lab technicians and volunteers was founded in Tehran.

Dr. Ala established a charity organization in England called “Friends of the Iranian Hemophilia Society” (FIHS), which has done a great job in terms of fundraising for the Iranian Hemophilia Society. Dr. Fereydoun Ala, who is also the Chairman of FIHS, said in one of his interviews, “Some 35 years ago I was able to establish the first centre for diagnosis and treatment of inherited bleeding disorders in Iran. Now, many years later I feel privileged to be closely associated, as Honorary President, with the new Hemophilia Comprehensive Care Centre in Tehran. This centre is well on its way to becoming a first class diagnostic and therapeutic focus of activity unique in the entire region. We have already organized four international seminars and workshops, and enjoy the dedicated support of the WFH. There is much still to be achieved but with the help and generosity of our supporters, the future is bright.”

(Top) Comprehensive Hemophilia Clinic, Tehran. From Left to Right: Dr. Irandokht Shoaei, Dr. Fereydoun Ala, Barbara Peters and Cyrus Salimi.

(Bottom) Physicians and patients form the Hemophilia Clinic of Isfahan, with Dr. Assad Haffar (third from left) of the World Federation of Hemophilia.