

by Julia Q. Long

## Helping the Patient, Knowing the Person

**P**roject SHARE<sup>SM</sup> donates millions of units of factor each year to patients in poor countries. Factor requests must be made on our official request form, which gives us basic information about a patient, including name, address, factor deficiency and amount of factor requested. This information provides a good overview of the patient's medical situation, but tells me little about the person behind the request. I learn more when I email or call the person making the request to find out more details. I learn about the patient's personal situation, and about the important people in his life. I have the honor to learn how patients are loved and cared for. I also learn about the people who, in turn, depend on them. And I find out what makes them happy.

Nanak Singh Nishter of Hyderabad, India is one of these patients. The 68-year-old grandfather of seven and his wife have two sons and two daughters. Nanak's granddaughter was the first to call us, seeking factor for her grandfather's upcoming surgery. Over time, through subsequent commu-

nication with her, and later with Nanak's daughter and Nanak himself, I learned not only about Nanak the patient, but about Nanak the person.

Of Nanak's three brothers, two were also born with hemophilia. But because so little was known about hemophilia in India before the 1980s, one brother lost his life in 1976 to an untreated bleed. Another brother's life was spared only by amputating a gangrenous leg.

In 1980 Nanak was diagnosed with factor IX deficiency in Bombay, where he was hospitalized with excessive bleeding from his gums. His daughter C.J. Kindra recalls her fear when she learned that he had hemophilia. "I was scared as I found out how life-threatening it could be, and I told him how I felt." But she thinks often of his words of consolation: Don't be afraid of hemophilia, but instead gain knowledge of it.

In the mid-1970s, Nanak began suffering from a hernia. For thirty years he lived in pain, in need of an operation. But it was impossible: The family lacked the 30,000 units of factor IX required for surgery.

Early in September 2005, Nanak's pain began to intensify. The Nishter family searched everywhere for factor donations so Nanak could have the surgery he had needed for so long. But at that time, factor IX was scarce internationally and the family had little luck. Project SHARE, however, had a few vials of factor IX. On September 16 we donated as much as we could—just over 20,000 units—hoping it would be enough for Nanak's operation.

Fortunately, Nanak's doctors determined that there was enough factor to proceed with the long-awaited surgery. On September 30, the head of the Medicine Department at Nizam's Institute of Medical Sciences in Hyderabad carefully supervised the dosages and administration of the factor throughout the operation. According to Nanak, the surgery was "successful, with no more loss of blood than a normal patient [experiences]."

Nanak is a theologian, social activist and writer. C.J. describes her father as "one of those real positive people who looks at a glass as always half full." Nanak stands by his belief that knowledge is better than fear, asking other people with hemophilia to live "carefully" and prepare themselves with knowledge of their disorder.

This gentleman who learned about hemophilia uncommonly late in life—at age 43—has brought the international face of hemophilia much closer to me. As Project SHARE requests continue to arrive daily, I increasingly appreciate my chance to learn about the people behind them: people with real hopes, real fears, loving families and unique lives who need our help. We assist more than 250 patients in more than 40 countries. My friendship with Nanak compels me to continue learning about the people behind the requests. And I will always remember the humble invocation in his latest email to me: "May God bless all mankind." 🌍



The person behind the request:  
Nanak Singh Nishter of India.



To make a donation of factor concentrate or money, or to obtain advice on donating factor internationally, please contact Julia Long at [julia@kelleycom.com](mailto:julia@kelleycom.com)

or visit

[www.kelleycom.com](http://www.kelleycom.com)