



# LIFE BEYOND PRICE

by Ana Narváez

Germán Navarrete Medina

At what price can you save a life? For Germán Navarrete Medina, it was a price he couldn't afford. Germán is 23 and has severe hemophilia. He lives in a slum in Managua, Nicaragua with his wife Rina and their three-year old daughter, Miriam Sarai. Germán is a taxi driver, earning only \$150 per month. It's a dangerous profession in this poor country. Germán is the only surviving male with hemophilia in his family; his uncle and brother died from untreated bleeds.

As if poverty and hemophilia weren't enough, Germán was also born with a kidney disorder that went untreated. Germán sustained permanent damage to his right kidney. In 2002, tests revealed a severe kidney bleed and loss of function. The kidney would have to be removed.

Germán was able to obtain free care at a public hospital in Nicaragua, but faced a waiting list of six months or longer. After he was placed on the waiting list, Germán's surgery was postponed three times due to hospital contamination, replacement of surgical equipment, and overcrowded wards. His condition worsened. Meanwhile, Germán had been unable to work for more than ten months. As a taxi driver, he was

photo: Ana Narváez



**Important Allies:** Dedicated hospital staff helped keep Germán on the road to recovery despite complications.

not covered by social security. He had no income, and could not pay for private health care.

I met Germán and his family in 1994 when I moved to Nicaragua and began volunteering for the Nicaraguan Hemophilia Association. As a volunteer, I serve as a liaison between patients and the international community. When Germán's health worsened, I helped a group of his friends and family members contact the Health Ministry to plead his case. Although we also contacted the Costa Rican and Venezuelan hemophilia communities for help, we found it less expensive to have Germán's surgery performed in a private hospital in Managua than have surgery abroad. Although still expensive, and with no immediate way to pay, surgery in a private hospital was the only way to save Germán's life.

Germán's surgeon, Dr. Francisco Frixione, was hesitant. An excellent urologist, Dr. Frixione unfortunately had no hemophilia experience.

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**Rough Conditions:** Unlike patients in the US, Germán faced surgery in a hospital with outdated equipment, contamination problems and overcrowding.

We explained the situation, and agreed on his and the HTC's involvement, surgery costs, hospitalization, recovery time and risks involved. Dr. Frixione and his team showed great compassion by lowering their fees. We now had a set date, a fixed price of about \$2,000, and no complications expected. But we needed the most important ingredient: factor!

We turned to Project SHARE and the World Federation of Hemophilia (WFH). We received 12,000 IUs from the WFH, 20,000 IUs from the American Red Cross and 150,721 IUs from Project SHARE.

On July 21, 2003, the big day arrived. Emotions ran high, but we were prepared. We arrived at the hospital like a tribe: Germán's grandmother, mother, wife, sister and daughter; my mother, my son, myself; a cooler with the factor, a backpack with Germán's clothing, and a few belongings in plastic bags. We hugged, laughed, talked and prayed.

Surgery went well. Germán was soon sleeping peacefully in the recovery room and everybody felt elated. But suddenly massive bleeding developed, and a second surgery was performed at midnight the same day. Ultimately, Germán had five surgeries in one week. His life was on the edge. Our initial budget couldn't possibly cover intensive care costs, and no one knew how long Germán would be there. He had respiratory arrest, cardiac problems and vocal chord damage.

The hospital bill alone rose an additional \$9,300—a fantastic sum in Nicaragua. It would take

**Getting Better, and Grateful:** Germán continues to improve at home with his wife Rina, thanks in part to Project SHARE and the many other people who opened their hearts.



photo: Ana Narváez

a lifetime of driving taxis to raise this amount. The Nicaraguan Red Cross kindly reduced the cost of the blood and blood products. The hospital further reduced its costs—but what else could we do? Germán's family discussed moving him to a public hospital to cut costs, but he wouldn't survive there. Thankfully, this did not become necessary.

Nicaraguan hospitals will not allow a patient to be released until the bill is paid. So we took out a loan to pay the bill and allow Germán to go home to his family when it was safe for him. When Germán came out of intensive care, he spent several days in his hospital room. When his factor levels were up and he was off the respirator, he was released.

Meanwhile, a patient with hemophilia in Nicaragua generously donated funds, as did friends of my family. But we needed more to pay off the loan. Through Project SHARE, people in the United States began to hear of Germán's plight. They generously opened their hearts and donated money—and they didn't even know him! The funds came in, and at last all of the hospital charges were paid. Germán could start life again, free of debt.

Germán kept bleeding for about eight weeks after surgery, but luckily received more blood transfusions. He was hospitalized twice. Now, almost 12 weeks after his initial hospital admission in July, he is on his feet again. While he continues to slowly improve physically, he has fully recovered his life.

Life with hemophilia is difficult in Nicaragua. But with the support of the community, life is bearable. We will never be able to personally thank everyone who helped Germán, but we deeply appreciate the compassion of so many people who opened their hearts to generously share in his recovery—people who value life above price. ☺

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