



PROJECT
SHARE

It's time to give back

Laurie Kelley

Simon's Struggle

In the US, we honor and reward people with bleeding disorders who excel in golf, karate, and even scaling mountains! These are all activities enjoyed by members of our community. In Africa, we need to honor people like Simon, who simply survive each day.

I met Simon, 26, in April during a humanitarian visit to Kenya. My partners on this journey were Maureen Miruka, founder of Jose Memorial Haemophilia Society–Kenya (JMHSK), and Paul Kamau, 21, a young man with hemophilia, who is administrative assistant for JMHSK.

To reach Simon's home, we drove nearly three hours north of Nairobi, deep into the Kenyan countryside, dodging terrible potholes. The shoulders of the road drop swiftly, so we had to be careful not to veer off. Unmarked speed bumps, or "sleeping policemen," blend in with the road and can cause severe damage.

We arrived in Nyahururu, a bustling town. The Kenyans are always walking, so I was surprised to see a long line of young men with motorcycles idling—the local transport. We spotted Simon sitting on the ground under a gas station sign, waiting for us. I gave up my front seat when I saw how painfully and slowly he was walking.

Simon directed us to his home via a road made of the red, rich soil of Kenya. As the road ascended into the hills, we dodged bicycles with massive loads of grass or wood, their drivers pushing them resolutely upward. Women and children walked, carrying huge loads of potatoes in sacks supported by bands around their heads. Cattle stumbled past us down the road into town.

Our tires spun in the muddy soil, but the car clambered up a dirt path strewn with rocks, and we finally arrived at Simon's farm, perched high on a hilltop with a spectacular view of the Kenyan countryside.

The farm is a rambling collection of split-log cabins and pens for animals. Rural living, even primitive, if judged by American standards. Simon's mother greeted us, but did not smile. The entire family was grim, tight-lipped. "They are stressed," Maureen told me quietly.

We all sat inside the small home, more like a shed, where Simon's mother lives. I glanced at the corrugated tin roof, typical in the developing world, the "wallpaper" of cardboard sheets stapled together, and the light peeping in through the gaps.

Simon hobbles on crippled legs. When he gets a bleed, this is what happens:

Photos: LA Kelley Communications, Inc.



Simon of Kenya: Rural living means hours to the nearest hospital

In pain, Simon must walk down the dirt path to the dirt road, and then walk three miles on this road down the hill and into town. There he waits for the local bus to drive him to Nairobi—to the only hospitals able to care for people with hemophilia. Our drive had taken more than two hours; the bus takes two to three times longer, with stops.

And all the time, Simon is in great pain.

It was clear to us all that Simon needs to keep factor at home. He knows how to self-infuse. But the Kenyan government buys no factor, so there is rarely any available.

We presented Simon with a gift of factor VIII, and we pledged that somehow, we'd keep him stocked with factor. By the time we shuffled back to the car, everyone was beaming—like a ray of light brightening his future—but no one more than his mother. Fortunately, factor from Project SHARE can help ensure that Simon survives. ☺

Read more about Simon, and about Laurie's trip to Kenya at <http://blog.kelleycom.com>

In rural Kenya, isolated hemophilia families suffer without factor

