



PROJECT
SHARE

It's time to give back

Laurie Kelley

Making History in Romania

Daniel Maruta, 35, lives in Tirgu Jiu, Romania, a southwestern city renowned for its outdoor sculptures by artist Constantin Brâncuși. Brâncuși lived here as a boy, and later was commissioned to create a memorial monument to World War I soldiers, located on the Avenue of the Heroes. Brâncuși's large, outdoor sculptures are now World Heritage sites: *The Table of Silence*, *The Gate of the Kiss*, *Chairs' Alley*, and *The Endless Column*—when you sit at its base and look up, the column appears to go up forever.

Endlessness is something familiar to Daniel, who has severe hemophilia A and grew up in Romania. Seemingly endless pain and hospital waits have been a way of life for him. And if having hemophilia weren't bad enough, Daniel has long suffered from collapsing veins. With repeated infusions, his veins weakened and became scarred; over time, the veins collapsed. As a child, he had received infusions of factor in his head, sometimes the only place where accessible veins were found. As Daniel grew, he had fewer and fewer usable veins; it was getting harder and harder to get factor into him.

Adriana Henderson, president of

S.T.A.R. (Start Thinking About Romanian) Children Relief, a US-based nonprofit that helps Romanian children with cancer or chronic disorders such as hemophilia, visited Romania last year and met with Daniel. He tentatively asked about having surgery to implant a port. A port is a medical device consisting of a small stainless steel reservoir with a quarter-sized silicone *septum* (partition or covering) on top. The port is connected to a vein by a tube called a *catheter*. Ports, commonly inserted into the chest wall, allow drugs to be infused without having to puncture a vein: the needle is inserted through the skin of the chest into the port's septum, directly beneath the skin. Drugs infused into the port find their way to a vein via the catheter attached to the port.

Adriana, who was born in Romania, hesitated to answer Daniel. No one with hemophilia in Romania had ever had port surgery. In fact, no one with hemophilia in Romania had a port. Not wanting to raise Daniel's hopes, Adriana didn't promise him anything at first. She told him that such a surgery required a lot of factor—about 50,000 IU, which



Daniel Maruta: First Romanian hemophilia patient to get a port

would cost a fortune in Romania. Because of insufficient supplies, any available factor is rationed and used primarily to help with emergency bleeds: an elective surgery like getting a port would be very low on the priority list for Romanian doctors. Still, Daniel was very excited. "He was so desperate for help," recalls Adriana.

Adriana contacted Project SHARE in April 2013. Over 12 years earlier, Adriana had also contacted us, when she met Nicusor, a crippled Romanian child with hemophilia. Nicusor had been promised factor to cover the surgery needed to correct his joint damage, but he had been let down repeatedly in the past when factor was not found. Project SHARE donated enough factor for his operation, but not until the factor was in her hands did Adriana let Nicusor know it had arrived. His operation was a success!

Hopeful again, Adriana turned to us to help Daniel obtain enough factor for his operation. Incredibly, a donation of factor was made to Project SHARE at the very same time that Adriana made her request. SHARE often runs out of factor, because the waiting list is long and worldwide, and the needs seem endless. But Daniel got lucky.

This summer, Daniel became the first Romanian hemophilia patient to have a port implanted. Though he is unable to work because of his disabilities, and he lives with his parents, Daniel now can give himself factor without trouble, thanks to his new port. And, in the process, he's also made hemophilia history in Romania! ☺

