



## *Ecuador:*

# No Shortage of Challenges for Hemophilia

Ecuador is a South American country of 13.5 million people, of whom approximately 700 have hemophilia. Project SHARE has helped Ecuador many times in the past with factor donations, and was chosen this year for a site visit, to allow us a better idea of its challenges and resources. Accompanying me was , general manager of LA Kelley Communications, who assists with all aspects of Project SHARE, and who speaks fluent Spanish. In a whirlwind trip that didn't waste a moment, we visited three cities in three days. Our escort throughout the trip was Marco Polo Taco Caceres, person with hemophilia and president of the Fundación Hemofílica Ecuatoriana (FUNDHEC)—the national hemophilia organization of Ecuador.

### **Tuesday, May 13.**

Zoraida, Marco, David (son of a person with hemophilia) and I caught the first flight to Guayaquil—a hot, humid, sea level metropolis. With an estimated 2.1 million people, it's Ecuador's most populated city. We were greeted by members of the Guayas chapter of FUNDHEC, and taken to the home of Guayas' director, Fernando Almeida and his wife, , whose son, Luis, has hemophilia.

We enjoyed a royal breakfast of homemade shrimp ceviche, popcorn, patacones and soda pop—typical Guayaquileño fare—before we attended a presentation at a public hospital. At the hospital, about 50 patients, families and doctors openly shared their thoughts and concerns about living with bleeding disorders. Fernando Almeida recounted how Project SHARE factor saved his son's life twice. Once several years ago, when he needed emergency abdominal surgery, and again more recently, when he suffered with a

head bleed, and was told he would die. I noticed that many people in the audience were dissatisfied with the distribution of factor. Patients living in Guayaquil felt that most factor stays in the capital, Quito, while patients living on the outskirts of the city said most of the factor serves the same families in Guayaquil. Afterwards, we toured the blood lab, and met several pediatric patients with hemophilia. Then, we squeezed into a very small car to make two patient home visits—a humbling and inspiring experience. Alex and his brother share a bedroom on stilts, which was built by a charity for the family. Here is a young man, with an amputated leg and finger, using his arms and rear end to climb and lower himself several times a day, up and down a dozen steep stairs. Alex has open wounds from frequent ascents and descents, and bruises. Alex also has a strong handshake and a warm, genuine smile. It was a challenge for me to maintain composure during sweltering heat and humidity, in addition to the rivers of people, the unruly traffic, the constant

threat of theft, and the hard to reach village we traveled to. But then I met Alex. I gained tremendous respect for him, and the people living with hemophilia in Guayaquil. Somehow, my composure no longer seemed so hard to maintain.

After two home visits, we enjoyed a late lunch with several FUNDHEC leaders, a couple of patients, and Dr. Francisca Ramirez, a private doctor who volunteers her time caring for people with hemophilia in Guayaquil. Then we were whisked back to the airport to catch an evening flight to Cuenca, except for David, who returned to Quito.

Cuenca is a smaller, "antique" city that, in contrast to Guayaquil, sits calmly in the mountains. It is home to about 400,000 people, including about 40 with hemophilia. We enjoyed a late-night dinner of typical Cuencan food, and retired exhausted but happy.





It's time to give back.

### Wednesday, May 14.

Today we were joined by Marco Taco, father of Marco Polo Taco, and also director of the Pichincha chapter of FUNDHEC in Quito. It was a cool and rainy day. The four of us were escorted through the city by Fausto Corral, person with hemophilia and director of the Azuay FUNDHEC chapter, and Silvana Sempértegui, mother of a child with hemophilia and former director of the chapter.

Our first stop was the public hospital Vicente Corral Moscoso. We met with doctors, and toured the blood lab, and pediatric and neonatal units of the hospital. Next, we participated in a presentation at the Medical College of Azuay. Marco (the younger) and Fausto spoke about local and national hemophilia care, reminding families that the various chapters of FUNDHEC are part of a single organization—one that can procure better resources such as training for their doctors and factor for the patients—as long as it maintains a strong, unified voice. Zoraida and I described Project SHARE's process of choosing which countries will receive our scarce factor donations. We encouraged them to work with their leaders to unite the organization, emphasizing that we are not the only ones who will pay greater attention. After the meeting, we stayed in the auditorium to meet with several patients and parents individually, as we didn't have time to travel to their homes. Seventeen-year-old Fernando had extreme hand and ankle contractures, and was painfully shy about them. He wouldn't look me in the eye when he spoke to me, and hesitated for some time when I asked to take a photo of his hand. Factor IX deficient, he is one of those who are not provided factor from the government. His mother raised

concerns about how hemophilia B patients are left out of government support.

Before we went to lunch, we toured the Red Cross blood bank, and met Dr. Pablo Monsalve, who is most involved administering factor to patients. Again, we grabbed a late lunch and headed to the airport to return to Quito. Our flight was delayed, so we managed to have a pleasant final meeting with Silvana, Fausto, Marco over coffee. We arrived in Quito that evening, and checked into our hotel.

### Thursday, May 15.

Early in our first morning in Quito, Marco Taco (the elder) drove us to the home of a patient on the outskirts of the city. Even though Quito has almost as many people as Guayaquil, the congestion was somehow more bearable, perhaps because of the temperate climate—75 degrees and a beautiful blue sky. The two visits were delightful. At the first family, four-year-old Johnny stumbled out in his Spiderman pajama top and bear claw slippers through his cluttered house to show us his physiotherapy exercises. At the second, four-year-old Joshua impressed us with his command of English, and carried on a conversation with his new stuffed animal throughout our visit in his more urban apartment building. We again found deep respect for the patients and families making their way through life with hemophilia and very few resources. We listened to the mothers painfully describe how they try to make the best possible decisions for their children, such as to forego physiotherapy in favor of a partial nutrition supplement, or to keep their son inside the four

walls of home, away from other children and dangers, despite family protests.

Site seeing is a luxury of time on these trips, but we did manage to gaze at the Virgin of Panacillo—a huge statue of an angel that boasts the best views of the city, and quite noticeably the least amount of oxygen!

The multi-storied Red Cross building houses the current headquarters of FUNDHEC. We met several members of the administration of FUNDHEC, toured the physiotherapy unit of the building, met two physiotherapists, and Dr. Cevallos, the principal doctor involved with requests from Quito. We learned the Red Cross had recently asked FUNDHEC to remove its office from their building because it was becoming too expensive to support. This is an example of the many problems faced by hemophilia non-profits in the developing world.

After touring the Red Cross building, we ate lunch and headed to the gathering at the public Hospital of Niños Baca Ortiz. In attendance were about 50 patients and families, doctors, Dr. Gonzalo Rivadeneira, Minister of Health, and representatives from the chapters in Manabí and Centro. Two family members stood up to thank us for specific Project SHARE donations that had arrived in time to save the lives of their loved one. Several young people enthusiastically expressed willingness to work with the country's other chapters to plan a better strategy to gain support



It's time to give back.

from within and outside of the borders of Ecuador. The Minister of Health spoke several times to pronounce his continued support of FUNDHEC, and to commend the work done by Project SHARE. The energy of this meeting was great. After this gathering, we met with hematologist Dra. María Barba, employee of the Ministry of Health, and co-founder of FUNDHEC twelve years prior, in her office. For about an hour, we witnessed patient after patient streaming in to discuss their medical needs. We all left her office around 6:00 PM. She was only paid to work until 12:00 noon that day. It was heartwarming to know that many patients who have so few personal resources are supported by this doctor who so obviously cares about them.

Oscar Puentes, country manager for Baxter SA, hosted us for dinner, along with the Minister of Health, and several representatives from FUNDHEC. It was a pleasant and animated end to a busy visit. We left our hotel the next morning for the Quito airport one final time. Twelve hours later we were in Boston—home once again.

While we undoubtedly could have used more time, three days of observations revealed that the people of FUNDHEC are with no shortage of challenges—insufficient quantity and types of factor purchased by the government, insufficient communication between chapters, geographic barriers throughout the country. Yet I was pleasantly surprised to see many important accomplishments—great support from the World Federation of Hemophilia, government-purchased factor (even 12% of the population with hemophilia A is a noteworthy step), and several excellent chapter leaders with progressive ideas

for improvement. I look forward to continued communication with my new friends at FUNDHEC, as we more effectively fold Project SHARE into FUNDHEC's plan to improve the lives of people with hemophilia in Ecuador.