

Patient's Perspective

“A Month of My Life”

by Karim Zamani

Hi, my name is Karim, and I've been coming to Children's Hospital and Research Center Oakland (CHRCO) for almost 10 years now—since I was 12 years old. I have beta thalassemia major, and I get blood transfusions every three weeks. Because of routine blood transfusions, thalassemia patients have too much iron in their bodies, and that's why we take Desferal. Desferal is a medicine that removes iron from the body.

The past few years have been tough for me because I haven't been compliant in doing my Desferal. I felt in top shape and physically fit! I didn't want to take it, because I didn't feel like I needed it. When you become sick and get a cough or a sore throat, for example, you immediately want to cure it because it bothers you, right? But I didn't feel any symptoms when I was becoming iron overloaded—until recently, when my heart started skipping beats! I told my doctors, and they said that it was critical that I do something about lowering my ferritin because it had (mysteriously) gone up to a very dangerous level of 7,600. I couldn't believe it, but I understood it was really time for a major change to prevent my heart and my other organs from failing. How was I going to explain this to my parents, since didn't want them to worry? But I did tell them, after my doctors suggested I come in to the hospital 48 hours a week and get intravenous Desferal. I continued doing this for about four months, but then my doctors informed me that 48 hours a week was not lowering my ferritin enough. Disappointed, I didn't know what was to come next. The doctors suggested being admitted to the hospital for one month to do Desferal intravenously for 24 hours a day.

I was shocked, but I agreed to their decision because I knew how important it was to take action right away. I really needed to get rid of all the excess iron that had been affecting my organs for so many years. I had one week of free time before I was admitted on February 1. I had a pretty flexible schedule for work because I am in real estate, so it was easy to get some time off. I said goodbye to friends and family and came to the hospital. I decided to get a PICC (peripherally inserted central catheter) so I wouldn't have to be stuck with needles all the time, and I think that overall, this was a great decision. The PICC procedure was very easy and painless, and it made it simple for my nurses to draw blood and administer Desferal through it.

The experience of being in the hospital for so long was terrible! Time went by slowly, and I gave up counting days. I would look at the clock and it would be 3 p.m. Two hours later, it was still 3 p.m.! I am ordinarily very active, but staying in the hospital for a month took away a lot of my energy, because I wasn't playing soccer, playing basketball, or running and jumping like I did at home. Even worse, now my appetite was gone, and hospital food was not my favorite! That's when my mom came, from our home in Vacaville, to my rescue. For the last two weeks of my hospitalization my mom stayed with me and got me back on my feet. I would take walks with her and she would cook food for me at the Family House which is a place parents and families can stay while their kids are being hospitalized for long periods of time. Finally toward the end, I was seeing better results! My ferritin had dropped to 3,400!

I was so happy when it was time to go home. I had missed my friends, family, and work so much! But I'm also really happy I made the decision to stay in the hospital for a month, because I saw great results! Now I'm continuing my Desferal at home, and I totally appreciate it so much more now! This all taught me a lesson, and from now on, I will take care of my body. I want to thank God for this opportunity, care, and health. I would also like to thank all my doctors, especially Dr. Vichinsky, Dr. Lal, Dr. Singer, and Dr. Golden; Elmo; ALL my nurses and charge nurses; Ozetta; ALL my PCA's; Suzanne and Rochelle from Child Life and all of the playroom volunteers; especially Scott; Beth; Toshi and her assistant; Ellen Fung, Dru Foote, and Jean-Marie Knudsen; Pinocchio, G-sus, Ron, and Azim; Mom and Dad; and especially Laurice and Matt for making my stay at CHRCO easy! Thank you! May peace be upon you all!