Battling Bruin: Summer

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My name is Summer Medford. I am 12 years old and a patient at the UCLA Mattel Children's Hospital. Shortly after my 10th birthday, I was diagnosed with onset systemic juvenile idiopathic arthritis (SJIA).

I remember being in perfect health one day, and the next day I was hooked up to IVs and lying in a hospital bed with stuffed animals surrounding me. At the time, I wasn't fully aware of what was going on, but I knew that it would take lots of effort to get better. After two hospitalizations, five teams of specialists and three surgical procedures, I was eventually diagnosed with SJIA, which is an autoimmune disorder.

My very first hospitalization was at Children's Hospital Los Angeles (CHLA), I vividly remember waiting in the ER most of the night for an available patient room. I was very lethargic and fevering like crazy. I experienced joint pain, to the point that I couldn't walk on my own. I had chills and didn't want to do anything, but sleep. My mom was by my side the whole time, but I could tell she was more concerned than I was.

Once I was admitted, there were two blood draws a day to monitor my inflammation levels and organ functions. Eventually I would need a blood transfusion because of my low blood count from fevering and high inflammation levels. Initially the doctors thought I had cancer, because of the many swollen lymph nodes in my body, especially my neck. So I had two lymph node biopsies along with a bone marrow biopsy during the course of my three-week stay in the hospital. We learned that SJIA is a diagnosis of exclusion, and because it has a lot of similarities to cancer we would have to rule out cancer before starting treatments for SJIA.

My mom did some research and found a pediatric rheumatologist at UCLA, which was much closer to home than CHLA. At UCLA, Dr. Alice Hoftman did not miss a beat, as she was able to pick up exactly where we were with CHLA. She advised that CHLA did a thorough work up which made it easy for her to jump in. Dr. Hoftman helped me understand my disorder a little bit better and find the appropriate medications.

I struggled a lot in the first year of trying to figure out what caused me to fever, have joint pain, lack of energy, face and body rashes, as well as trying to explain to my worrisome friends that I will be OK. Although the doctors, my family and I still don't know the cause of my flare-ups, we figured out a way to manage them.

2017 was a rough year, as I kept flaring, and we were having a hard time getting it under control. Did the medication stop working? Was I growing? Is it an infection? Or is it a secondary malignancy from being on immune suppressants for so long?

When the outpatient procedures were not as effective as we hoped, UCLA Pediatric Team was quick to respond, and made sure the transition to hospitalization was as smooth as possible. I was admitted three times from September 2017 to January 2018, for extremely high inflammation levels, which could result in macrophage activation syndrome. I had to be hospitalized to make sure my organs did not shut down. I was given many medications and shots each day, along with daily blood draws at 6 a.m. I also had to have another surgical lymph node biopsy to rule out cancer again.Every morning I would wake up trying to put a positive outlook on my day. I walked around the hospital ward with another patient. He had his feeding tubes attached, and I pulled my oxygen tank. I prayed that everything would be alright for all the patients as we passed by the doors.

Throughout this two-and-a-half-year journey, I spent lots of time all over the UCLA medical campus seeing different specialists and have always been greeted with a smile. I believe they truly care about how I am doing. UCLA Children's Clinic, the Infusion Center and Hospital have been like a second home, and the staff is like extended family members. The Child Life Specialists help me transition from clinic to hospitalization, and make sure there are fun activities during our stay.

Each and every hospital stay has its memorable moments. I will never want to forget how amazingly Dr. Hoftman, my other doctors, nurses and Child Life Specialists took time to help meet my needs for healing and happiness. Being in the hospital, I became very educated with different medications and grew a close relationship with the staff and volunteers.

Now that I’m out of the hospital, I continue to strive optimistically, knowing that I have an amazing health program by my side for life. Even though I’m not completely free from SJIA, I believe that someday I’ll be out there helping other children get through the same struggles I’ve been through.

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