

We Watch and Wait – Living with Rare Disease

Erdheim-Chester disease is not the same for all patients.

By Tina Koslosky

My name is Tina. I am a 56-year-old woman diagnosed in 2018 with Erdheim-Chester Disease (ECD) and Langerhans cell histiocytosis (LCH). My doctor believes I likely had the disease for years.



The diagnosis started quite by happenstance. I was at work feeling sick and could take it no longer, made an appointment, left work and went to my Primary Care Doctor (PCP). My PCP, Luigi Buono, DO is a no non-sense kind of doctor. Matter of fact, bottom line kind of guy. MY kind of doctor. So when I told him we had had Chinese food for dinner last night and I had since had indigestion, horrible burping and malaise, he said here take this, a stomach remedy, but you know you always have weird things happen- go get an abdominal ultrasound. Which led to a CT scan. And then a PET scan. I knew when I saw the tech's face, something was up. I lit up like a lantern on the PET scan. There was something near my pancreas, on my medial spinal nodes, liver and spleen. We were then referred to the Imbert Cancer Center to Dr. Marisa Siebel. She is a warm fuzzy version of Dr. Buono and we loved her immediately. She said she would not say I had cancer and they would keep doing biopsies and such until they had an answer. We had not told our then 22-year-old daughter, 17-year-old son or 12-year-old daughter anything. Nevertheless, when they said biopsies, we knew we had to say something. The Imbert Cancer center has whole host of specialties to assist the patients, including social workers. We talked it out and my husband and I let the kids know, something was up, but we didn't know what.

First up was the biopsy of the pancreas area. Dr. Jaspreet Singh took nine biopsies and was stumped- nothing. NOTHING. Then onto liver biopsy- not my favorite with Dr. Alper. NOTHING again. Ok- so now I had to have my spleen removed. Before I could get the pre-op testing done, I got the flu and bronchitis. With the delay, Dr. Siebel agreed to another PET scan since it had been three months. The previously biopsied areas were not reactive, but the spleen still was and so we knew we had to take it out. So on May 21, 2018, Dr. Gary Deutsch took my spleen out via robot. It took nearly a month of testing to finally come to ECD and LCH.

Compared to others, I am what I call asymptomatic. I suffer from fatigue, but so far, not too much else that could at that time be blamed on the Histiocytosis. So the surgeon and the oncologist suggested I take time and shop for a doctor I could live with since I would have to see this doctor a lot. We had been down this road before. We lost a son to leukemia in 2000 and due to his condition, really did not have any options. So they said, go interview them. We live on the eastern end of Long Island. New York City is still doable and easy.

We chose Dr. Eli Diamond at Memorial Sloan-Kettering Cancer Center (MSKCC) in July 2018. In the months following that visit, I have had periodic PET scans and we are in a watch and wait mode. September 2019, I asked that the fatigue be addressed. It was affecting my day-to-day life too deeply. I started on Ritalin, which has been a game changer. It also helped change my overall outlook being more positive and upbeat. Tomorrow, I have another PET scan scheduled and pray for a continued watch and wait mode.

Tina Koslosky