

Unexpected Hope in Israel

An Erdheim-Chester disease patient tells her hope-filled story for Rare Disease Day 2021.

My name is Meir Layosh, I'm 36 years old, married to Yocheved and father to Yuval, Daniel and Amit, who is one year old. I wanted to share with you my story, since it's Rare Disease Day.

On May of 2019, while on vacation, I received a call from my surgeon – who operated on me two months earlier. Apparently, the lesion that he excised from my eye was abnormal. He did not linger – and instructed me to consult a hematologist promptly.

I saw a local hematologist, who informed me that I'm diagnosed with Erdheim Chester Disease – a rare type of cancer. The lesion in my eye, apparently, was a tumor. Another consult with Dr. Google, was an incredibly stressful experience, as I learned that very little is known of this disease.

I felt the ground shaking beneath my feet. Besides being upset with my condition, I was confident that it would take months to locate the right physicians who would manage my condition.

Nonetheless, a quick search of the web led me to the specialists at Assuta Medical Center. Within minutes, I had the phone numbers of Prof. Ofer Shpilberg & Dr. Roei Mazor from the institute of hematology. I never guessed that I would be speaking at that very evening with the doctors who will treat me and provide me with a solution that will prolong my life and improve it markedly.

In less than four days, I performed a PET/CT and brain MRI scans that shed light on where the disease resided in my body. Regretfully, the scans showed that my brain, skeleton and kidneys were all involved with tumors.

Dr. Mazor then recommended to recruit me to the Make an IMPACT trial at the Memorial Sloan Kettering Cancer Center – in an attempt to identify the mutations that are driving my disease's progression. Identifying such a mutation, he said, might give us the information needed in order to tailor a targeted treatment for my disease. When the test results came back, Dr. Mazor indeed prescribed me such a drug. In less than three months after I started therapy, the tumors appeared to regress. More than a year after starting treatment I'm still in remission.

Today I live with the treatment and I'm carefree. Not because the disease disappeared, but because I'm confident that I'm in good hands. I know that Dr. Mazor and Prof. Shpilberg are available to address any problem that might emerge in the future. I could not have hoped for a better team to take care of my health and be there for me. This is my opportunity to thank you above and beyond – for everything.

The clinic of Histiocytic Neoplasms at the Assuta Medical Centers network is a dedicated clinical service for the diagnosis and treatment of histiocytoses via a precision medicine approach. Dr. Roei Mazor explains: ***“By unearthing the tumor’s weaknesses on the molecular level and by harnessing our understanding of the disease’s biology, we are often able to offer our patients personally tailored treatments. There is still much to achieve and the challenges that we face are indeed substantial, however, I’m confident that in due time, medical experts will be able to harness this approach for the treatment of other malignancies as well.”***

The molecular laboratory at Assuta, headed by Dr. Oshrat Rokah, focuses on the research of Erdheim-Chester disease among other histiocytoses. The lab studies the pathogenesis of these diseases and attempts to characterize novel molecular biomarkers that might aid in the disease's diagnosis as well as predict potential response to therapy.

