How One Doctor Saved His Own Life

David Fajgenbaum, MD, crowdsourced treatment for the lymphoma-like Castleman disease. His research may help find new drugs for COVID-19.

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When David Fajgenbaum, MD—then a medical student—was diagnosed with multicentric Castleman disease, a rare condition characterized by the overgrowth of cells in the lymph nodes, he was already on his deathbed. Now, in his book Chasing My Cure, Fajgenbaum recalls how he crowdsourced his own treatment using an international network of doctors, scientists and patients, reports NPR's Fresh Air. He also shared his story as a keynote speaker at the world's largest cancer conference, the American Society of Clinical Oncology (ASCO) annual meeting, held virtually last week.

While still in college, Fajgenbaum took care of his mother, who had been diagnosed with Stage 4 glioblastoma, a type of brain cancer. Before she died, he promised her he would dedicate his life to treating and researching diseases to help patients like her.

Then, one day, during his third year in medical school, Fajgenbaum became a patient himself. He was experiencing flu-like symptoms, abdominal pain and more before being admitted to the intensive care unit, where blood tests showed signs of liver, kidney and bone marrow failure.

Things got so bad that Fajgenbaum went blind in his left eye, was on kidney dialysis and underwent daily transfusions. Yet he left the hospital without a diagnosis.

Then Fajgenbaum ended up in the hospital again and was tested for lymphoma. He didn't have lymphoma but rather idiopathic multicentric Castleman disease, a rare condition that has characteristics of both cancer and an immune system disorder, he says.

Although he was treated for several attacks of Castleman, it wasn't enough. So Fajgenbaum took it upon himself to find a cure.

"It wasn't easy," he told NPR. "But the way that we started out to try to solve this problem was that we first tried to identify all the physicians and researchers and patients worldwide who knew anything about Castleman disease." The plan was to first find everyone, connect them and then see if he could crowdsource from them. He wound up connecting over 400 researchers and 1,000 patients. Together, they launched over 25 studies.

“In the midst of this progress, I graduated from medical school and got engaged to the love of my life,” he told the ASCO audience. “Then I relapsed and needed multi-agent chemotherapy to save my life again. I knew I wouldn’t make it to our wedding day unless I found a drug to keep me in remission, so I dove headfirst into research.”

He mapped out the changes in his T cells before his relapse and eventually discovered a drugable target—one that an existing drug already targeted for a different disease. Eventually, Fajgenbaum took a leap of faith and started taking sirolimus, an FDA-approved immunosuppressant drug used to prevent rejection of organ transplants. “Amazingly, thankfully,” the drug worked against his disease.

After nearly dying five times, Fajgenbaum it’s been almost 77 months since his last relapse. “The New York Times called this ‘doctor cure thyself,’ which I think is a bit of an overstatement, as I could relapse any day,” he told the ASCO audience. “But during this remission, I was able to make it to my wedding day and marry my wife.”

Fajgenbaum believes that the harnessing of engaged patients and researchers may hold a key to producing future breakthroughs in cancer and other diseases. It’s an approach that other groups, such as Count Me In, a patient-partnered research initiative, are using as well.

His research may even help in the treatment of COVID-19. Castleman disease affects cytokines, a group of chemical messengers produced by immune system. One way that COVID-19 turns severe and sometimes fatal is a “cytokine storm,” an extreme immune overreaction that can lead to multi-organ failure. Fajgenbaum is currently using his research approach to systematically track all drugs used against COVID-19 and to search for existing drugs that might be repurposed against the pandemic disease.

“Hoping for something takes more than casting out a wish to the universe and waiting for it to occur,” he said. “Hope should inspire action. And when it does inspire action in medicine and science, that hope can become a reality beyond your wildest dreams.”

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