A Leukemia Diary: 24 Years With CLL and Still Playing Golf

Terry Evans, 76, a father of four, lives with his wife in Huntington Beach, California. He has had chronic lymphocytic leukemia since 2000 and is active in the CLL Society.

March 6, 2024 As told to Bob Barnett

April–June 2000

My job as IT manager for Long Beach, California, allowed me a physical every year. My doctor asked me if I had been sick, because my white blood cell count had gone up the last three years. It was still in the normal range, but he sent me to a hematologist. The hematologist ran blood tests and, in a follow-up in June, told me I had chronic lymphocytic leukemia (CLL) [a cancer that affects white blood cells]. I was shocked. I felt fine. He tells me I have cancer, and it's incurable, but we're not going to do anything about it right now. I was confused. I went home and told my wife, then my four kids. The youngest was 18. The internet told me I have a five-to-10-year life span. I was 52.

Terry Evans leads support groups for the CLL Society.Courtesy of Terry Evans/Matthew Evans

July 2000–April 2007

For seven years, I almost ignored it. I retired in 2005, after 33 years at my job, partly because I wasn't sure if my disease would progress. My white cell count was going up, but slowly. I had no symptoms. My wife wanted me to see a CLL specialist, but I kind of ignored the disease.

May–September 2007

I felt fatigued, was losing weight. We were helping our daughter move out of her house in Florida and back to California, and I was stressed. There's a link between stress and disease progression.

My white blood count doubled and then doubled again. By September, it was 600,000—normal is below 11,000. My hematologist said it was time to treat. He gave me a monoclonal antibody and then a combination of an antimetabolite and a chemotherapy drug.

[I was pretty sure I had] developed autoimmune hemolytic anemia (AIHA). Your body attacks your red blood cells, so your hemoglobin drops. I was so tired I couldn't stand up in the shower. But my hematologist refused to acknowledge what I had. My wife, who is a nurse, said, "This is ridiculous."

November 2007–May 2008

My wife contacted a CLL specialist in England, who responded that there was a 95% chance I had AIHA so I made an appointment with a CLL specialist in San Diego. He saw us quickly, confirmed the diagnosis and told me my hemoglobin was so low that I would probably have gone into cardiac arrest within 48 hours. I was admitted to the UC San Diego Medical Center and transfused. It was my 60th birthday. They started treating me with high-dose steroids. That got the autoimmune condition under control, but then it came back.

June 2008–April 2010

It was determined that the CLL was causing the AIHA, so they started treating me with the monoclonal antibody along with the high-dose steroid, which drives the cancer cells out of lymph nodes and into the bloodstream, where they can be killed. You feel great, like you could run a marathon, but two days later, you don't want to be near me. It puts you into a real funk. I started to realize how foolish I had been by not seeing a specialist earlier.

Around this time, I saw a post on an internet forum about a CLL support group meeting in Newport Beach, 10 miles from my home. I had never met anyone with CLL. There were seven or eight people, including the leader, Brian Koffman, a family doctor with CLL. He went on to found the nonprofit CLL Society. I've been involved ever since.

Treatment brought down my numbers. I thought we had a winner. I had a 13-month remission.

Then we had to repeat the treatment. This time, a five-month remission. Time to try something new.

Terry and Donna Evans with their grandchildrenCourtesy of Terry Evans/Matthew Evans

May 2010–September 2012

I opted for a clinical trial that included a BCL-2 inhibitor [which blocks a protein that prevents cancer cells from dying]. I was on the trial for nine months, and my numbers looked good for another 18 months.

Our CLL group grew to 35 or 40 people. It's run by patients and caregivers, not doctors, which lets people speak freely. It was the greatest thing in the world to be able to share and get information directly from patients. When Brian asked me to lead the group, I said yes. We started meetings in other cities. We'd fly people in from New York or Orlando or Houston, and I'd train them in our model. I still manage all these groups—there are now 45—and lead the Orange County [California] one. Since COVID, our monthly meetings are all on Zoom.

October 2012

I was beginning to relapse quickly, so I entered another clinical trial, which compared two drugs: a covalent BTK inhibitor [which blocks a protein called Bruton tyrosine kinase that can promote

cancer growth] and a monoclonal antibody. I got the latter. My CLL numbers went back to normal, but in two months, after stopping the monoclonal antibody, they started to climb again.

August 2013

There was no crossover, so I couldn't take the BTK inhibitor, which had an amazing 85% response rate. The CLL community thought this was unethical—that by not allowing crossover, they were allowing patients to die—and petitioned the FDA [Food and Drug Administration] to change the rules. That happened, but it took months.

I was out of options. On a Tuesday, my doctors told me to come in on Friday for stop-gap treatments. But on Thursday, the FDA approved the crossover. If I had started the [stop-gap] treatment, I probably would have been kicked out of the trial.

October 2013–2017

I started the BTK inhibitor and immediately saw a reduction of my spleen and lymph node swelling. Two years later, my white blood cell numbers were normal.

2018

My CLL numbers started rising, so I entered another clinical trial, testing a combination of a BCL2 inhibitor along with the BTK inhibitor. I had to pay $12,000 a year for a co-pay, but it seemed to be a winner. Within 16 months, I had "unmeasurable minimal residual disease"—they couldn't find any CLL.

Terry and Donna Evans on a trip to Israel.Courtesy of Terry Evans

2021–2022

After 29 months, we stopped one of these drugs. We thought the remission was deep, but [the decision to stop] was partly financial. The CLL came back, so we tried the other drug by itself. That didn't work. We went back to the combination, which kept it under control, but my CLL numbers were rising.

In August 2021, I was diagnosed with prostate cancer. People with CLL often get a secondary cancer because our immune system is screwed up. I'm on active surveillance, but it's treatable.

January 2023–Present

Because I get frequent blood tests, we saw signs of relapse in January of 2023. I was refractory [resistant] to both the BTK inhibitor and the BCL2 inhibitor, but I heard about a non-covalent BTK inhibitor, which works by a different mechanism. I started this new drug in June, and it appears to be working. I have very few, if any, side effects.

I don't expect a cure. Nor do I expect this to be my last treatment. I hope it will last a long time. I pretty much just live my life, even when relapsing. We've been to Hawaii four times. This year, we'll go to Ireland. Several times a year, we visit our four wonderful children and 12 grandchildren.

I play golf once or twice a week. I’m living a pretty good life.
