A Leukemia Diary: Brian Koffman, MD

A family physician when diagnosed with chronic lymphocytic leukemia, Brian Koffman cofounded the CLL Society. He lives in Claremont, California.

August 2, 2021 By Bob Barnett

September 2005

We were living in Newport Beach, California. We had four young adult children, two boys and two girls, and the last were off to college, so my wife, Patricia, and I were empty nesters, able to enjoy ourselves. I was 54, a family doctor.

I noticed when I was showering or brushing my hair that I had some lumps at the back of my neck. I wasn't too concerned. I thought they were just cysts. But they didn't go away. Months later, I ordered some bloodwork on myself. As the saying goes, the doctor who treats himself has a fool for a patient.

I remember getting the results back and seeing that my cholesterol was excellent. I was pleased, but my white blood cell count was too high. Next thing I knew, I was seeing a hematologist, getting a fancier test called a flow cytometry, an immunological fingerprint of the cells. I soon learned that the reason my count was high was that I had leukemia, namely chronic lymphocytic leukemia, or CLL.

October 2005

My oldest daughter was getting married in October. We're Ashkenazi Jews, and in the Jewish tradition, there's a teaching in the Talmud, which is commentary on the Bible, that when a funeral and a wedding procession reach the same corner at the same time, the wedding procession takes precedence. Choose life over death. So we decided not to tell anyone until after the wedding was over.

It was a lovely wedding, but it was a very difficult time for me and Patricia because everyone was in a celebratory mood. I had gotten some prognostics back that suggested I had a really bad variety of CLL and a short time to live. Not only was my CLL incurable, but there were no treatments that were shown to prolong survival. None.

Winter/Spring/Summer 2006

CLL is a relatively orphan disease, meaning it's quite rare—a little over 20,000 new cases a year. The average hematologist sees only one or two cases a year. I began to find experts who were

doing cutting-edge research on CLL and ran around the country to get other opinions. I had a form of CLL that was very likely to be nonresponsive to chemotherapy. I was relatively young, so I tried to think outside the box. What else could I do?

I tried traditional Chinese medicine. I tried acupuncture. I changed my diet to vegan, which I've stayed with ever since. I tried a raw diet, but I was just losing too much weight. I was exercising, meditating, trying to reduce stress in my life.

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September 2006

I noticed some little red dots on my legs. Again, I did the foolish thing and ordered labs on myself. I was on call when I got the message on my own blood test that the results showed a critical level. My platelets, which prevent bleeding and bruising, should be over 150,000, but mine were 9,000. That was a dangerously low level, and the red dots were a sign of bleeding under the skin.

I called my hematologist, and within a couple of hours, I was in the hospital receiving emergency treatment. I had developed a rare autoimmune complication of CLL— immune thrombocytopenic purpura (ITP)—which was attacking my own platelets and causing internal bleeding. It was a really tough time. Over the next year and a half, I was in the hospital five times for low platelets.

February 2007

I had an emergency splenectomy (removal of the spleen) to see if it would raise my platelet levels.

My belly was black and blue from internal bleeding, and my lymph nodes were growing from CLL. I grew a big Santa Claus beard to hide my lymph nodes from my patients. But they could see that I was not well.

Over the year, I got various treatments to get my platelets going, but finally, a combination of a monoclonal antibody and an immunosuppressive drug started to work. Unexpectedly, these drugs also worked well against my CLL. My platelet counts normalized, I was feeling better and my CLL was knocked back.

April 2008

I decided to go for an allogeneic hematopoietic stem cell, or bone marrow, transplant, from an unrelated donor. It was a radical decision, because it's usually a desperate Hail Mary pass made as a last resort. I was having it upfront, as my first therapy. But I had nearly died a few times. It was extremely unlikely that chemotherapy would work for me. So why not go for a transplant? Yes, it carried a significant treatment-related mortality, but it was the only thing that offered me a potentially curative therapy.

It was hard to find a donor, but eventually, a perfect match was found. It was scheduled for the end of June. Meanwhile, I had to let everyone know, so I was busy writing emails, but my kids said to me, "Dad, that's so old-fashioned." At their suggestion, I started a blog to tell my story. It morphed into something bigger after I recovered from my transplant. I started attending major hematology meetings, learning about new compounds that were coming and reporting the news in a patient-friendly format on my increasingly visited blog.

July 2008

I had my stem cell transplant on July 1. Unfortunately, it didn't work. I never engrafted. Within a few months, my ITP was back, and my CLL was back. Luckily, when I went back on the old meds, I gained some control of the ITP and CLL again.

2009

I was on intravenous immunoglobulin (IVIG) for my ITP and stayed on my raw vegan diet, green tea, taking copper and zinc, flaxseed, vitamin D-3. I wrote in my blog, "Still meditating. Still working out. Still being positive in thought and action." I thought, My real hope lies in a redo transplant and not much else.

2010

In January, my platelets and other counts were good, but I still had palpable nodes from my CLL. My blog had more than 100,000 visits since July 2008.

During a period of feeling well with relatively stable labs, I went to Israel between my regular IVIG infusions to meet my wonderful bone marrow donor.

2011

In May 2011, my CLL was back and was being aggressive. I wrote, “My maneuvering has bought me almost 5 years but it hasn’t been enough time to find the cure. Not even close.” By November, the enlarging lymph nodes in my gut were causing problems. I wrote that my doctors “disagree on most everything EXCEPT that I need therapy. Soon.”

I was hearing a buzz about new compounds that were coming. Like all very new medications, they didn’t yet have names, just numbers. These were oral targeted therapies that would ultimately revolutionize the care of CLL.

In December, I went to the annual meeting of the American Society of Hematologists (ASH). I met a doctor in the hall, one of the top CLL researchers, and I talked to him about his trial of one of these new molecules, and he said, “Yeah, we’ll pencil you in.”

Traditional chemotherapy works by killing all fast-growing cells. They have significant side effects, including hair loss, nausea, vomiting and diarrhea, anemia, low platelets and a suppressed immune system.

A better approach is to find if there’s anything specific about the cancer that you can target. In CLL, they discovered that it was addicted to a signaling pathway, and they found ways to knock out that signal downstream. I took the very first drug that was successful in doing that. Today, we have many different targets, and targeted therapy is used in many cancers. When I came back from ASH, I wrote in my blog, “Let me just say that the world of CLL is changing, and changing for the better.”

January 2012

My wife and I moved to Columbus, Ohio, for January, February and March to start on my clinical trial with the targeted drug that saved my life.

When I enrolled, I had significantly enlarged nodes. I remember showering two days after starting the trial drug. I was washing my neck and under my armpits and thinking, Is it possible the lymph nodes are shrinking already? They felt softer and smaller. By the end of the week, there was no question that they were melting away. Soon, they were gone and stayed gone for years. I stayed on that drug for several wonderful years, until I slowly relapsed.

2015

A blog by its nature is chronological, a vertical way of sharing information. People who were newly diagnosed with CLL—who didn't know what a lymphocyte was, what a spleen did—were reaching out to me. I wanted to teach people so you didn't have to be an MD or attend major hematology conferences to benefit from the best and latest therapies. I think, as a physician, we have an obligation, because you can see around corners, you can shine a light down the road.

With my wife, I started an educational website, CLLSociety.org. That was the birth of the nonprofit, the CLL Society. The other major aspect was support, because there are things that one CLL patient can tell another CLL patient that you can never get from a doctor. We started with one support group near where I lived in Orange County, California. Now we have 38 support groups across the country. Our website gets visited between 80,000 and 90,000 times a month.

2017

I developed a rare mutation in my CLL—my cancer cells learned how to turn the pathway back on that the drug had blocked. I slowly started to relapse. Time for another option. At that time, there were two options available—a different class of targeted therapies or CAR-T— chimeric antigen receptor T-cell therapy. I went with CAR-T. It's a living drug. It was certainly the more dangerous choice, and it was only experimental—it's still not approved for CLL. But I knew my CLL tended to be difficult to treat and recurrent, so I was giving it the biggest kick I could in the hope of getting rid of it for as long as possible.

March 2018

My wife and I flew to Seattle, to the Fred Hutchinson, Seattle Cancer Care Alliance. I was the 36th patient in the trial.

With CAR-T, they take your T cells, a type of white blood cell, out of your bloodstream and "ex vivo" [outside the body] genetically alter them, inserting viral messages to recognize the cancer and attack it. When the cells are reinfused, they sleep for a while, and when they wake up, they're trained killers. It unleashes a killing frenzy, a cytokine storm of inflammation.

It was a difficult time for me. I had night sweats, fevers and terrible pains. I had two hospitalizations. I was confused. I couldn't make good decisions for myself. My wife had to care for me and make the decisions. When you're out of it, you don't know you're out of it. For example, I thought that it's normal that people were green. I was hallucinating, and I couldn't put two sentences together. It was hardest on my wife. She's watching this and is wondering, Is he ever going to go back to normal? Is he ever going to talk again? To walk again?

But I got through it—I fully recovered—and when they restaged me a month later, I had no evidence of cancer in my blood or bone marrow. All my lymph nodes had shrunk back, essentially, to normal.

Time to celebrate. The Seattle Cancer Care Alliance is near a lake, and there are seaplane tours. We booked a flight. My wife is deathly afraid of flying in small planes, but she did it, and we loved

it. We went out for a fancy dinner together; we Skyped with our kids. We were just ecstatic. It was an incredibly wonderful time, and I do want to emphasize that if it wasn't for Patty, it wouldn't have been possible. I mean, she just stood by me.

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July 2021

Testing shows that in my peripheral blood and bone marrow, one in a million, or less, are cancer cells. Both my treatments—the targeted therapy and the CAR-T—were in early Phase I clinical trials. I'm an early adopter. I was willing to take risks, and my timing was great. If I had been diagnosed two years earlier than I was, I wouldn't have had these options.

The nonprofit CLL Society continues to evolve. I like to say that we provide patient-friendly but physician-curated information. It has now had well over a million visits. We've started doing our own research. We've presented at ASH three times. We're linking with many nonprofits, working on issues such as how we respond to COVID-19 vaccines. CLL patients may not form adequate antibodies and therefore may not be protected postvaccination.

I am now 70. I am no longer on any active treatment for CLL, but I remain immunocompromised. I take prophylactic antibiotics and antivirals to prevent problems. I've entered another trial, this time to receive passive antibodies for COVID-19 that should protect me for six months or more.

I've had different professional lives. I loved taking care of patients as a family doctor. The rewards you get for helping people as their doctor are amazing. But now the CLL Society needs my full-time attention, and there, I can make an even bigger impact. While I can't provide direct medical advice, I can counsel them about what they need to do. I've published half a dozen papers that have advanced the field of CLL. Most family docs don't get to say that.

I walk every day. In the summer, I swim every day. I see my children and grandchildren. In the last year, because of the pandemic, I've spent a lot of time on Zoom. I cook and bake. I'm writing all the time, and some of it is only peripherally related to CLL. It's about how you make decisions about health.

Before the pandemic, I traveled 100,000 to 200,000 miles a year, mostly work-related, but after I had lectured or done interviews, we might spend extra days exploring the highlands of Scotland or the streets of Dublin, Amsterdam, London, Paris or Madrid. I love art and museums. I love studying architecture and history. As the world opens up again and if we can find ways to protect vulnerable folks like myself, I'm hoping to do more traveling and lecturing and reconnecting with friends again.

I'm Canadian, and the last big trip we did was in Canada just before COVID-19 stopped the world. We spent days canoeing in a Canadian national park. As much as I love being in nature or seeing the world, what I am really hoping for is to be safely with my family and friends again.

To learn more, see the website for the CLL Society and Dr. Brian Koffman's blog.

To read more about people with CLL, see "A Cancer You Can't Cut Out," "Shakespeare, Meet Leukemia", "Youngish With Cancer" and Jeff Neurman's blog. To read about CAR-T for a person with non-Hodgkin lymphoma, see "Pioneering Patient."
