

My Journey with Cutaneous Lymphoma

As shared by Joe C.



It all began in 1993 when Joe began developing unidentifiable patches on his body. The first one, which he calls “patch #1”, was on his right thigh. Having lived a very active lifestyle, which included many outdoor activities such as boating, Joe was diligent about his annual visit to the dermatologist. He was sent home with a prescription for a mild topical cortisone cream and was told that the patches would clear. But they didn’t. They continued to get worse and additional patches slowly began to develop.

Mystery Patches

Joe’s dermatologist finally recommended that he see the head of dermatology at a clinic in Arizona. At the time, Joe’s insurance denied coverage of the visit to the clinic because it was out-of-network, and they recommended that he see another in-network dermatologist. So he did, and it was the same story from not just one but two additional dermatologists. “Nothing to worry about. Continue to apply the topical creams and you should see your skin clear up.” Finally in April 1995, two years later, and after working with his original dermatologist to fight the insurance company, Joe was finally approved to go to the clinic in

Arizona.

The new dermatologist conducted a thorough examination, which included skin biopsies, blood work, bone marrow biopsy and gene rearrangement studies. In June 1995 Joe would receive an answer, an answer that would forever change his life. He was diagnosed with mycosis fungoides.

The Doctor Told Me Not to Worry

“When the doctor first said I had cutaneous lymphoma, the word lymphoma didn’t register for me. The doctors told me not to worry, so I didn’t. They told me it would be something other than cutaneous lymphoma from which I would die.” So, Joe went home with a treatment plan that included topical steroids and PUVA treatments at his local dermatologist office. Over the next few years, Joe would undergo more than 200 PUVA treatments and a variety of topical creams to try to keep the disease under control. But, as time went on, the disease continued to progress. It continued to worsen.

By late 1998, Joe developed a tumor on his right ring finger. He went to see his dermatologist, who took a biopsy which came back as squamous cell carcinoma. Joe was referred to a hand surgeon for excision of the tumor. The removed tissue was sent to a specialty lab in California. The results came back that the tumor was actually CTCL.

Joe began to search the Internet for as much information and he could find on CTCL. He needed to find a doctor who knew more about the disease. In early 1999, he eventually came across a doctor who formerly worked at a clinic in Ohio and specialized in CTCL treatment and research. He had recently moved to Arizona and was right in Joe’s backyard. Joe made his first appointment.

I Need to Take This Diagnosis Seriously

Joe brought the results of the biopsies and all his files to his appointment. Joe’s worst fears were confirmed. His disease was transforming. His disease had become serious and it was time to be more aggressive. “For the first time, I realized that my disease had taken a turn and it was bad. For the first time, I realized that I needed to take this diagnosis seriously. For the first time, I realized that what I was dealing with was cancer. For the first time I was scared.”

Beginning in the summer of 1999, Joe began an aggressive treatment of total body radiation. “For the first time my lifestyle was changing. Up until this time I was boating and water skiing, my wife and I spent lots of time at the lakes, we travelled a lot going scuba diving. It all changed right then and there.”

After 36 radiation treatments, which took place over the course of several months, Joe’s skin began to heal. He had all of the expected side effects of the radiation – he lost his hair, his finger nails and toe nails fell off, his sweat glands weren’t

working normally. The treatment had consumed his life, having to go 3-4 times each week, but the treatment worked.

Times I Felt Better. Times I Felt Worse.

But, within a few months, the new patches, plaques and tumors began to develop. The results of the radiation were short lived. extra corporeal photopheresis (ECP) was added to his treatment plan shortly after total skin electron B therapy (TSEB). Interferon was added in early 2000 along with several additional spot radiation treatments. This new medication came with its own set of challenges. Joe self injected the medication 3 days each week. “I felt less like myself. New tumors were developing all over my body. I was tired. I was worn down.”

Joe began to become discouraged and didn’t know what the future would hold. “Thoughts I used to have were “am I going to be able to see my grandchildren grow up? I didn’t know if there was a light at the end of the tunnel. By 2000 I had so many symptoms, flare-ups everywhere. They’d come and go. They were cyclical. Times I felt better. Times I felt worse.”

Physician Who Lived and Breathed CTCL

By the end of 2002, Joe had reached a breaking point. He felt that to survive this disease, he needed to take control. Once again, he turned to the Internet, searching for a clinician who specialized in CTCL—and eventually found a leading expert whose work focused on the disease.

“My symptoms were getting worse. I wasn’t happy with my life or where this was going, and I felt like I needed the heavy artillery.” Joe scheduled his first visit in the fall of 2003. After a thorough exam, blood tests, and skin biopsies, the specialist added Targretin to his existing regimen of ECP and Interferon.

Follow-up testing confirmed that Joe’s MF had progressed to Sézary syndrome. For the next six years, Targretin and ECP helped stabilize things, although he continued to experience cyclical “breakouts” of rash and erythroderma. “I wasn’t sure if the treatments were really helping. I still had flare-ups and lifestyle challenges. My hands were so bad I had to wear white cotton gloves. I wondered—if I stopped everything, what would happen? Was this as good as it was going to get?”

Over the next few years, Joe’s Sézary cell counts climbed, and his symptoms intensified. By summer 2009, his lymph nodes were enlarging—some growing to the size of chicken eggs. A biopsy confirmed large cell lymphoma. By late 2009, Joe was miserable and desperate.

His care team decided to change course. All treatments were stopped in October 2009, with plans to start oral Zolinda. “Things immediately went from bad to worse. I could barely function.”

Around this time, the CTCL specialist Joe had been seeing was preparing a new clinical trial and suggested it might be an option. “I literally begged to get on this trial as quickly as possible.” By Thanksgiving 2009, Joe was enrolled. Within weeks, his symptoms began to ease. His blood counts stabilized, his skin improved, and his lymph nodes shrank.

Stem Cell Transplant

For the next year, Joe felt better than he had in years. “My wife and I were able to travel again. I felt like I was getting my life back.” But by late 2010, his lymph nodes began enlarging again. During this period, Joe was also introduced to a transplant specialist who recommended preparing for a stem cell transplant (SCT), suggesting it was his best chance for a cure.

In order to treat the lymph nodes, Joe would have to come off the clinical trial and try other chemotherapies. Romidepsin was first, then Doxil. Neither produced results on the lymph nodes but Joe’s skin and blood continued to be much improved and the Sézary symptoms were nearly gone.

Then came a breakthrough. Early in 2011, another oncologist collaborating in Joe’s care suggested an IV chemotherapy combination known as GDP. After the first infusion, his largest nodes shrank by 75%. By the third infusion, they were no longer palpable, and imaging confirmed they were clear. With this success, a donor was identified in Europe, and preparations for transplant moved ahead.



Emotional Roller Coaster

Preparing for the transplant came with its own set of emotional issues. Joe suddenly found himself feeling extremely anxious about the welfare of his donor. Would the donor get into a car accident and not be able to harvest the cell? Would the donor get sick? He worried that something was going to go wrong. Joe and his wife needed to find a place to live near the hospital, more than 700 miles from his home in Arizona. They would need to live there for five months – to uproot their lives. It was a lot to deal with. And, not many transplants had been done on CTCL patients. At his treatment center, Joe was patient #11.

By May 2011 after a number of frustrating delays, including issues with the donor's personal schedule, the transplant was scheduled. In June, Joe, his wife and 2 dogs and as much as they could fit in the car, drove to Palo Alto. That Monday Joe began his second round of total skin electron irradiation, to be followed by total lymphoid radiation and a series of IV drugs. He was hospitalized for 5 days the week prior to the actual transplant and was on an emotional roller coaster. "My biggest worry continued to be, and I stressed a lot about this, was my donor. The cells are harvested the day before the transplant and they are couriered to the hospital. They have to be tested by the transplant center first to make sure it was indeed a match. I was scared to death that I went through this entire process and something would happen – a car accident – anything. My donor was in Europe and they came from a long way."

Good News...the New Cells Were Taking Over

Typically, three critical outcomes determine the success of a transplant: 1) the transplant has to take – the new cells have to takeover your cellular identity 2) your avoidance of graft vs. host disease. This outcome is the most critical after the transplant. 3) Finally, the intended effect of eliminating the cancer has to happen. "I hit all three. I couldn't have been happier, although I had a lot of doubts along the way and there were definitely tough days during the 90 days following the stem cell infusion. I contracted three different infections, would start to feel like I was getting better, and then get worse again. It was a rough process and there's a lot that can go wrong. But, after my first HLA (chimerism) test, we were called with good news. The new cells were taking over." Joe's transplant was a success.

Throughout the process, Joe had a network of hundreds of family and friends, including the listserv, cheering him on, and supporting him every step of the way. Joe sent email updates to his group he calls his "spiritual army," a periodic ritual that provided an outlet for him to talk about his transplant journey. The healing came with some struggles, including infections, the Epstein Barr Virus, PTLD and Joe had to undergo a round of intense chemotherapy shortly after the transplant to treat that.

I Have My Life Back

By early November 2011, more than 5 months after Joe and his wife moved to California, it was time to go home. Everything was going great. The donor cells were taking over (90+%), his cancer markers were under control and even continued to drop. Joe and his wife returned home to Arizona, still on immune suppressant drugs. Within 3 months, he was off of all medication and today, he's on no medications at all. "I have no symptoms and I feel great. I started this process when I was diagnosed at 45 years old and finally at 63 I had my life back."

Throughout his journey, Joe attributes his positive attitude and strong faith to helping him get through on the tough days, of which there were many. Once he took control of his care, became informed about the disease and the treatment options that were available to him, he felt a sense of hope that he would come out on the other side of this disease. The support from his loving wife who stood by his side every step of the way as his primary care giver and source of strength, his children, family and friends also helped him push on when the bad days just wouldn't seem to let up.

Joe's advice to other patients facing a similar journey is "take control of your disease and your care. Be informed. Know the protocols. Know your options. And, never lose hope. If you can keep your attitude positive, you can ride through the bumps. You can't sugar coat a stem cell transplant. It's not an easy road. You have to set aside 5 months of your life. You feel sick. It will wear you down. But the end will justify the means."

It's been almost two years since Joe's transplant and he's loving life again. He's traveling, enjoying the outdoor activities that he once had to give up. He's looking forward to the future, his grandchildren and a long life free from the symptoms of CTCL.