

## **Memo Victim CHRISTINE SHEPPARD**

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#### **SHORT BIOGRAPHY**

#### Oceanside, California

We are originally an English family. In 1980 my husband, Ken, who is a degreed mechanical engineer then working in aerospace, was offered a job in California, which came with a fast-track visa opportunity. So we, and our young daughter, moved to the United States and eventually became US citizens. In 1995 we bought a coffee farm on the Big Island of Hawaii, in the Kona coffee growing region. In August 2003 I was diagnosed with Stage 4 Large B-cell Non-Hodgkins Lymphoma, with a 10% chance of survival. After a year of chemo treatments that had not cleared my NHL, we sold the farm so that I could undergo a stem cell transplant at City of Hope in Los Angeles. The stem cell transplant did not completely remove the NHL so I had a monoclonal antibody radioimmunotherapy treatment, which put me into remission. We are now retired and living in Oceanside, California. I am still in remission. But I DO suffer what are called the late term effects of the chemo, radiation, and stem cell transplant. These include very painful CIPN (chemo induced peripheral neuropathy) which gives me severe foot and hand pain, controlled to some extent by drugs; thyroid deficiency, again controlled by drugs; high cholesterol controlled by drugs; thickened heart wall, monitored by yearly tests; night blindness; and an extremely low immune system which leaves me vulnerable to long illnesses that other people shake off in a week.

### History of Round Up Use on Farm and Non-Hodgkins-Lymphoma

We are originally an English family. In 1980 my husband, Ken, who is a degreed mechanical engineer then working in aerospace, was offered a job in California, which came with a fast-track visa opportunity. So we, and our young daughter, moved to the United States and eventually became US citizens. By 1994 we were both working in the high tech industry. My husband was an Engineering Director at a hardware company, and I was a Director of Marketing for a software company, that involved worldwide frequent travel.

Our jobs had enabled us to make savings for a good retirement, but we were tiring of our hectic life. We had saved enough to do something totally different that was less financially rewarding so we researched a different plan - a lifestyle and work that would allow us to spend our time together, and that would last for the rest of our lives. We were fit and active, regularly doing 50 mile bike races, and wanted to do something that involved our own labor, and together. Somewhere we could settle for the rest of our lives, and enjoy through old age. So when my husband was 50, and I was 47, we decided to try our hand at a long-held dream, coffee farming.

We bought the farm in 1995, on the Big Island of Hawaii, in the Kona coffee growing region. It was a five acre coffee farm that had been let go, completely. The owner only used it for the house and the view. The weeds were so high that we could hardly wade through them, and the coffee was trees instead of bushes, tall with many branches twisted together.

We were still living in San Diego, wrapping up our jobs and moving out of our house, so we arranged for the realtor to have someone go in and get rid of the weeds. This was done with RoundUp, which was standard for the coffee growing region, and the recommended choice of the University of Hawaii College of Tropical Agriculture agent in Kona.

For nearly a year, in our vacation times, we would spend two weeks hand pruning the 2,000 coffee trees, about a third of which we had not even known were there. The agent found them when they started spraying the lower half of the farm, as they were young trees that the weeds had completely covered up. Then another two weeks bringing in the first harvest.

In 1996 we moved over to the farm permanently, and being totally new farmers, we carried on the practices that were common in the area, including both of us spraying RoundUp on the weeds, with a backpack sprayer, several times a year. We did this for the next five years.

Our life on the farm was wonderful. We worked really hard, manual labor that kept us fit. People had questioned what we knew about growing coffee, and we learnt really fast, from the local agricultural agent and from many incredibly wonderful neighbors. The skills we brought from our previous jobs made our business successful. I built a website to market and sell our coffee, and it was one of the first Kona coffee websites ever. My husband built, or refurbished processing equipment, so that within a year we were able to take our coffee from seed to cup right there on the farm. We never had to sell at stores, which cut into profit margins. We sold every fresh-roasted and packaged bean either on our website, or to visitors to the island who would stop for a tour of the farm. I was elected to be President of the Kona Coffee Council, then the premier organization for the coffee industry in Kona. My husband was their director of education, organizing seminars and workshops for new and experienced farmers alike.

Our farm also became a sanctuary for animals that needed rescuing. Over time, we had ten cats that we neutered and released onto the farm, two dogs, two donkeys, and two goats that we took in at a few days old as, being males, they were destined to be slaughtered.

In 2001, after meeting with the newly formed Hawaii Organic Farmers Association, we formed a plan to take the farm organic, a five year process, which involved marking off borders between our farm and our neighbor, who still used RoundUp, so we had a ten foot buffer, as required by HOFA for eventual certification. However, before we could accomplish that, I became ill – extreme fatigue, shortness of breath, night sweats. I assumed it was my age and menopausal. But then my leg swelled up and was extremely painful. I thought it was blood poisoning, but my doctor thought it was a blood clot in my groin. After treatment with blood thinners, which failed to do anything, I had an ultrasound to find the bloodclot. Instead of a blood clot the ultrasound found numerous enlarged lymph glands including one that was in my groin and causing the leg swelling. I was immediately given chemotherapy, while they biopsied one of the glands. In August 2003 I was diagnosed with Stage 4 Large B-cell Non-Hodgkins Lymphoma, with a 10% chance of survival.

The regime of treatment that was going to give me any chance of survival to was arduous and time consuming. Every third week I had a six-hour session of chemotherapy at a clinic an hours drive away. The effects of the chemo were severe. For the next week after that I was so sick I could only move from bed to bathroom. On the second week I could get up and get around the house for short periods. The third week I felt well enough to do some work on the website, fulfill the incoming orders etc. Then the cycle started again.

We had both been completely hands on, working ten-hour days, and loving it. I did all the website work, milled and roasted the coffee, packed and shipped the orders, as well as pruning in season, and helping with the harvest. There was no way that my husband could take on my jobs on the farm as well as his own, and in addition look

after me while I was so sick. I would look at him in my "good" weeks and see he was getting worn out, and that essential jobs were slipping out of control.

We had a family conference and decided that the only way I was going to survive cancer, and him survive too, was if we sold the farm.

The other consideration was that, at that time, we had very little hope that I would survive, and I could not die and leave Ken to cope with the farm, the animals, selling up, and all that it would entail, by himself. We were "clearing the decks" for whatever the eventuality would be. I knew that Ken would want to either go back to California to our daughter and grandsons, or maybe to his family in England, if he lost me.

So we put the farm up for sale. My chemo continued for 8 months, with multiple visits flying from Kona to Honolulu on the island of Oahu for various scans that were not available in Kona.

We sold the farm and moved out in April 2004, to a rented studio cottage. It was the hardest thing I had ever done. It was our paradise, our place for the future, and I was devastated at losing my goats, donkeys, dogs, cats, and life style. I was sure then that my life would shortly be over.

Shortly after moving to the rented cottage, I had a scan and it showed that the regular chemo had only partially removed the lymphoma, so I flew to Honolulu for several high-dose chemo sessions. Once again, this did not completely remove the lymphoma. My oncologist told me that my only available option was a stem cell transplant. I spent several weeks undergoing rigorous tests of all my organs to make sure that I was strong enough to undergo such an invasive procedure. He had applied for me to go on a trial of a new stem cell transplant procedure at City of Hope in Los Angeles. After reviewing all my tests, they accepted me for the trial.

So we moved into a friends house in California so that I could go to City of Hope.

I went into City of Hope in July 2004, and underwent more tests, and was told by the senior oncologist in charge of my case that although I had qualified for the trial, the trial did not start its next patient intake for six weeks, and they did not think that I had six weeks left. This was shocking and distressing news, but, because I was there and an admitted patient, they could perform the standard (rather than the new trial) autologous stem cell transplant. They started this procedure immediately.

During all of the testing phases for the several weeks before this I had had to have injections of neupogen, which stimulates bone marrow production. My medical insurance, as well as not covering 100% of any of the treatments I had had so far, did not cover Neupogen at all. The cost of every and each injection, given daily, was more than \$350 per injection. In order to pay our medical expenses and buy the necessary

drugs, we had to cash out my retirement savings completely.

A stem cell transplant is an extremely severe and arduous treatment, including very high dose chemo, and three sessions a day for a week of full body radiation. The recovery is very slow and painful. City of Hope REQUIRE that each patient have a relative or friend to be their supporter, and monitor them. I was there for four months. For three of those months my husband was there, staying in a rented motel-style room. My sister came out from Florida to help me for a month, also staying in rented accommodation.

In October, my oncologist at City of Hope pronounced me fit enough to travel, and I returned to our rented cottage in Hawaii. We still had hopes of perhaps restarting our farm life, if all went well. However, after my December scan, we found that I still had lymphomas in my abdomen.

My oncologist in Kona suggested that I try Zevalin, a new monoclonal antibody radioimmunotherapy treatment just out of trials, given by injection. It had not previously been given to patients who had had a stem cell transplant, so several researchers calculated a dose and I was given it in April 2005. My husband was instructed not to leave me alone at any time, as I may collapse and need help. For the next few weeks I had several transfusions of platelets and blood to stabilize me. It removed the lymphomas and I have been in remission ever since.

However, my immune system was now severely compromised, and unlikely to improve - a result of the numerous treatments. My oncologist said that a return to farming was not an option. Many people die from infections caused by their weak immune system after cancer treatments, and farm work presented too many chances of injury and infection.

So my husband took up building coffee equipment for other farmers. And I remained involved in the various coffee associations doing PR and marketing for them, until we moved back to California to be closer to facilities that I might need. We now live in Oceanside, South California

Since I learned of the link between RoundUp and NHL, I have become convinced that this was the cause of my NHL.

I am still in remission. But I DO suffer what are called the late term effects of the chemo, radiation, and stem cell transplant. So far, these include very painful CIPN (chemo induced peripheral neuropathy) which gives me severe foot and hand pain, controlled to some extent by drugs; thyroid deficiency, again controlled by drugs; high cholesterol controlled by drugs; thickened heart wall, monitored by yearly tests; night blindness; and an extremely low immune system which leaves me vulnerable to long illnesses that other people shake off in a week.

My lifestyle and enjoyment of life is impacted most by the CIPN – constant

low-level pain, loss of balance, loss of confidence in driving, fear of not having my pain relief drugs constantly at hand. And by my low immune system, which makes travel, parties, group events, a challenge to be weighed up against the probability of getting sick.

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