

CANADIAN CANCER SURVIVOR NETWORK

First off, I would like to thank the Canadian Cancer Survivors Network for inviting me to talk about my story.

Prior to my diagnosis, I led an active lifestyle, was a non-smoker, non-drinker and I thought I was doing all the right things to be healthy.

I grew up around marching bands playing the tuba. I started in the Burlington Teen Tour Band where I met my wife Kimm. I then helped start the Burlington Top Hat Marching Orchestra. I used to be in a drum and bugle corps running around football fields in Canada and the US with a 30lb tuba on my shoulder. When I came home after a performance in the fall of 2013, I had muscle spasms in my back. I went to an after-hours clinic where the doctor suggested I have a chest X-ray. From this point on, my life took a dramatic turn.

It turned out to be 1.5 litres of fluid in my left lung. I went to the emergency department where I had a chest tube put in to drain this fluid. After testing, I was diagnosed with cancer. A few weeks later I was having chest and side pains. I had 3 litres removed for a second time.

During this time, I was given the devastating news that not only did I have cancer, but I had stage 4 Non-Small Cell Lung Cancer that had metastasized to my brain, bones and liver.

I was shocked and overwhelmed with sadness by this news. I felt that I had months to live. Right away I worried about my wife. I worried about my 2 children and how they would cope with losing their father.

My daughter was in her 4th year of university and I worried how this would affect her success in school. There was nothing I could do about it. My son had recently graduated from university and starting his career. I was worried how this would affect their lives. I worried about my career and how this would affect my position at work. How would I be able to deal with all that was ahead of me. My life felt like it was spinning out of control. This was not only affecting me but my entire family.

I went offline and I didn't contact people because I couldn't handle having to explain my diagnosis over and over.

I was sent to the Firestone Clinic at St. Joseph's Hospital in Hamilton and they inserted a tube to drain the fluid from my lung. A nurse came to our house 3 times a week to drain the fluid. The fluid stopped about 6 months later, and the tube was removed. During this time, I was going for chemotherapy twice every 2 weeks, having my chest tube checked and cleaned, having an MRI of my brain and then seeing my brain oncologist every 2-3 months. Then CT of my chest and pelvis every 2-3 months with follow up at the cancer clinic. I also had 2 full body bone scans in Nuclear Medicine.

I had bone strengthener IV injections every month or so to help the healthy bones. I still have these injections every 3 months. During this time, I developed 2 blood clots and after hospital visits, was put onto Fragmin and then later on was switched to Coumadin.

It was quite hard on my family with juggling everyone's schedules to get me to my appointments. This stage of my treatment was extremely overwhelming, and I developed anxiety and depression. Up to last winter, I have been on 3 different chemotherapies and one immunotherapy. The chemotherapy treatments did help me but each one did run its course. I did not respond to the immunotherapy.

I was lucky as I tolerated the chemo quite well. The last treatment I was on though did damage my body more and I lost my appetite as well as over 20lbs. I also had damage to my hearing and require hearing aids now. This is permanent.

After each session of chemo infusion, I would wonder if this would be the last one. After each scan to my Brain or Chest and Pelvis, my anxiety skyrockets as I know within a week, I will be yet again sitting in worried anticipation that the oncologist will walk through the door and give me bad news. As a cancer patient, this is repeated over and over again for 6 years.

My employer gave me the opportunity to work from home and I was paid in full. I worked from home while I went to doctor appointments and treatments. After one year my employer expected me to return to the office to work. I was unable to commute to Toronto and work 5 days a week. I had no option but to go on Long Term Disability. At that point my employer discontinued my health benefits and wouldn't let me pay into the group plan, this created even more anxiety.

My Oncologist was always keeping watch for new or future treatments. She found something and was able to send a sample of my cancer down to Boston. Unfortunately, this turned out to be incompatible. The people in Boston asked if they could continue using my Cancer sample for further testing and of course I said yes!

When I started my last chemotherapy, I was informed that they had isolated my specific genetic mutation. There was a possibility a drug VITRAKVI would work for me.

My Oncologist right away started to work on getting approval for me as I was running out of time with the chemo that I was on. This drug had not been approved or Clinically Tried in Canada but had been in the US. I don't know how she did it, but I am so thankful to her.

The only side effect that I have right now is fatigue.

I have seen my daughter graduate from university, my son get married and the birth of my grandson. Over the last 8 months I have been slowly getting my life back.

I went from appointments every two weeks to appointments once a month. I have noticed a dramatic lifestyle change. I am regaining my strength, I feel like I have my life back, and I am able to enjoy my family and friends.

Thank you for listening to my story, not everyone's story is six years in the making.