

Carol Joy Patterson – Spirit of Hope

My life so far has been an exciting journey, punctuated by a cascade of medical events. Never a dull moment. You don't know how you'll respond to bad news until you are faced with it. I've had plenty, but there has always been hope.

It began the day I was born a healthy ten-pounder. As a medical experiment, I received an enormous dose of radiation to shrink my thymus away in the hope of preventing SIDS. This was just months before doctors realized x-rays were harmful. Alas, most of this guinea pig group of babies developed thyroid and other cancers about thirty years later.

For me, the initial cancer encounter came at a time when I had been very excited to film a story about the 'Snowbirds', the Canadian Air Force's precision aerobatics team. They don't let just anyone go up in a two-seater fighter jet, even as a passenger. The high G-loads, barrel rolls and inverted flying are very demanding so you have to pass a battery of pre-flight tests. I was doing great in all the crazy centrifuge machines, but then during the physical exam, the alert Air Force doctor detected a subtle lump in my neck. He'd discovered the thyroid cancer early, but it required immediate surgery. That was the beginning of my journey through "cancer land".

I'd already switched from teaching high school and college English to being Canada's first news camerawoman. I travelled around the world, met many famous people and received quite a lot of press attention as a pioneering female. This new career was so exciting and fulfilling for me that I couldn't let the threat of thyroid cancer slow me down. Fortunately, the operation to remove it was successful. We'd caught the cancer in time, but no-one mentioned that my DNA had likely been compromised by that radiation as a newborn.

Then, while producing and filming a CBC-TV broadcast of a World Cup race

in 1985, I was hit by an out-of-control skier 'racing' in a tuck. I was concussed for quite a while, and it turned out that I could never carry a heavy camera again. But in our company, TV2GO Inc., I still could produce mainly television sports films, in partnership with my wonderful husband. I also learned I was pregnant with the first of our two children. That kept me from dwelling on my misfortune. So did adopting a little girl from China in 1998.

In 2002, though, I first learned I had been diagnosed with breast cancer in a cellphone call from a surgeon. On a stormy Friday night, I was just walking into the home of actor Michael Douglas to record his voiceover for a Super Bowl spot. Since I began shaking with surprise and dread, he and my crew likely assumed I was nervous meeting such a star! Next day, my husband went with me to see that surgeon, but since then I've prided myself in going alone to every doctor's appointment. It's my way of trying not to take cancer too seriously.

What I hadn't known all along was that my regular mammograms were being misread by radiologists. I had had breast cancer for twelve years before they finally realized that it was not just "calcification" they were seeing in the x-rays. My dense tissue was hiding the tumor. Rushed into surgery within ten days, I lost a breast, but very kind surgeons scrambled to rebuild it immediately on the table. I chose to be delighted by that reconstruction because – full disclosure – my personal vanity demanded it. I lost my hair during chemotherapy. I looked on the positive side...being grateful we caught it in time and that I could try new haircuts and colors and wear wigs for a while. I always wore makeup and colorful clothes and kept working to keep my spirits up. We all felt I should avoid x-rays and CT scans the rest of my life whenever possible.

Breast surgery and rebuild was repeated in 2004 on my other side, but no more chemo was necessary. I tried to stay calm and positive. It sure helped to have a supportive spouse, friends and an active career.

I was still blissfully unaware that more cancers could develop, most likely from that heavy radiation at birth. Almost everyone on both sides of my family had lived well into their nineties, with no cancer other than some carcinoma, so I doubted my cancers were familial.

Then in 2011, I and my GP 'discovered' a softball-sized GIST (tumor in the lining of the stomach) in time to remove it with skillful surgery. Again, I chose to feel lucky. Indeed, I still can eat anything even today.

You'd think this would have been the end of the cancers. Unfortunately, not. Soon thereafter, a very alert oncologist performed a bone marrow biopsy on me on a hunch, and advised me he had found Waldenstrom's macroglobulinemia. "What's that?" I asked. "Look it up on the internet", he said. The internet told me I had only five years to live! Needless to say, I searched for and found another doctor, through the terrific WM support group I immediately joined. That group is full of ten- and twenty-year survivors.

Initially, my status was 'watch and wait' for this indolent, incurable cancer. My oncologist did not prescribe any drug or chemo treatments. After two years of trying various iron supplements with Vitamin C unsuccessfully, several infusions of iron upped my hemoglobin count a little. However, I found myself still overtaken by fatigue, which became my constant companion. I chose not to worry, because I and my oncologist both felt my positive lifestyle would stave off the WM advance. I cut back my office time, continued exercise classes, ate healthy foods, participated in two book clubs, sang every Monday in a choir (performing twice at New York's Carnegie Hall), became a grandmother, and took art lessons. I had to take daily naps, though. This strategy worked for quite a while. "Just keep doing what you're doing," the doctor said. I even acquired a red 1953 MGTD sports car, and raced it across Newfoundland in a 2016 rally. That turned out to be a bit of overreach, as the initial exhilaration eventually turned into exhaustion! That experience taught me that trying new things and looking

forward with confidence is about the best one can do.

Then, another medical issue developed. I believe that my ski accident long ago, with its concussion, probably caused me to develop Parkinson's disease. I had lost my sense of smell right away. Then, in 2006, I suddenly developed shakiness in my right hand, and found myself unable to cut my own meat or sign my name. After a determined search, and attempts by three neurologists, I found a top expert who prescribed just the right medicine combination for me. Now I have no symptoms except nighttime sleep disorder. Since I felt, sadly, that I should give up my weekend skiing, I joined a local Rock Steady boxing group for PD patients to keep up the all-important physical work. I realized this disease is progressive, but nevertheless I have adhered to my philosophy that it's harmful physically and mentally to worry about such matters ahead of time.



This attitude contributed greatly to preserving the quality of my life and spirit right up to the moment late last fall when routine monitoring and labs showed my WM was starting to move into alarming action. So, in January 2018, when my watchful oncologist started me on Imbruvica, I felt further confirmed in my determination not to have fretted about WM all those years. My rapid and robust response to the therapy caused the drug

company to cite me as one of their star patients. I won't pretend there haven't been side effects, but they seem a small price to pay in return for my dramatically improved recent blood test results. It's so nice to have a good hemoglobin count again!

I feel it's important to be a partner with the doctors in the care of one's self. It's not just about finding the right medicine; it's also about sustaining positive attitudes and committing to changes in lifestyle that can make a huge difference. It's gratefulness for living in a country with universal healthcare, women's rights ... and indoor plumbing! Now I paint sunrises instead of sunsets.

Carol Joy Patterson

Toronto, Canada

May 2018