

Do you know what most Lung Cancer patients look like? Let me introduce you to one.



This is my wife, Merita. She was a healthy vibrant working Cardiac Intensive Care Nurse. She was never sick. In fact, her primary physician was her Obstetrician/Gynecologist! It wasn't until Merita was feeling under the weather around Thanksgiving in 2014 and went to the local emergency room early Saturday morning after Thanksgiving with severe back pain.

The Emergency Room performed a CT scan of her chest and discovered a plural effusion and pneumonia. This was a complete surprise because Merita had not exhibited any symptoms of a pneumonia. We assumed it was just exhaustion from preparing for the holiday.

Merita was admitted to the local hospital on Monday afternoon at the recommendation of a Pulmonologist so she could receive intravenous antibiotics and have the fluid drained from her lung. She spent four days in the hospital before being discharged to home care with a two week supply of two powerful antibiotics.

Two weeks passed and on the 18th day after discharge her back pain once again increased. She was re-admitted to the hospital due to increased fluid and consolidation in her left lung. More fluid was drained and then it was decided to do a VATS procedure to remove the consolidation from her lung. Upon trying to access the lung the consolidation was too thick and the Thoracic surgeon decided to perform a full Thoracotomy. This is where they cut open your back and then cut open your lung to scrape the consolidated material from the lung. In the process the Thoracic Surgeon performed a partial lobectomy removing the lower portion of her lung.

Post testing of the material from Merita's lung resulted in a benign finding. But, Merita continued to have pain in her back in the same location. She was repeatedly told that the pain was referred pain from the major surgery. Finally, while visiting our family doctor he was palpating her spine and caused her to have excruciating pain. He decided to take an X-ray of her back and saw a shadow on her thoracic spine. He immediately ordered an MRI of her spine.

My wife completed the MRI and we were informed that there was a three-level tumor growing on her spine and it would require immediate surgery to remove as much as possible before it paralyzed her. There was no option. The Neurosurgeon had to perform a triple laminectomy to remove three sides of the tumor, but could not remove the tissue from the anterior (front) of the spinal cord due to the possibility of causing paralysis. Testing showed lung markers in the tumor tissue. My wife had Stage IV Non-Small Cell Lung Cancer, Adenocarcinoma. We were devastated, and naively believed this was an error because my wife had never smoked in her life.

I took my wife to MD Anderson to receive treatment. They immediately took a biopsy of a small mass in her lung via needle biopsy and confirmed what the local Oncologist reported; that she indeed had lung cancer. We were told by the local Oncologist that my wife needed immediate chemotherapy and radiation. The prognosis was about five months to live. MD Anderson told us to go back home. I was shocked and demanded to know why they weren't treating her based on what we were told at home. Their response to us was that my wife is young, otherwise healthy, and a never smoker, which means she may have a genetic mutation that is driving her lung cancer. If she was to receive traditional treatment it may limit her response to oral drug treatment if she does have a genetic mutation. We were to return in two weeks.

The waiting was excruciatingly long. As the test results started trickling in, it was not looking good. The most common came back negative, the next, and next kept coming back negative. We were finally told that one last result was pending and that it took the longest to determine, but to not get our hopes up because only 5% of Lung Cancer patients have that genetic mutation. It's a mutation called Anaplastic Lymphoma Kinase, or ALK. I immediately did research on this mutation and discovered that it had the most promising drugs and several were in drug trials and the response was being reported as very positive. I prayed hard that my wife had this mutation. We got a call in a day or two from MD Anderson and we were told that my wife had hit the lottery and that she has the ALK mutation. This isn't a lottery I ever considered would be a good one to win, but in this case it was. My prayers were answered.



My wife took her first dose of Crizotinib on May 2nd, 2015, known by the retail name of Xalkori. It is a Pfizer drug. Her response was immediate and obvious. She was feeling wonderful in two days, and at 12 weeks she was deemed to have No Evidence of Disease (NED). We were all very ecstatic and believed she was on the road to recovery. We were going to be able to lead a somewhat normal life together. But that was short lived. Eight weeks later she became symptomatic. She started losing her field vision in her right eye and was having some balance issues. We were told that Xalkori did not do a good job of penetrating the Blood Brain Barrier and offered little to no protection of the Central Nervous System (CNS). We were fearful of brain metastasis and immediately went to MD Anderson. After numerous scans we were told my wife has developed a rare complication known as Leptomeningeal Carcinoma (LMC)/ Leptomeningeal Disease (LMD). This complication is normally only diagnosed in 20% of cancer patients, but found via postmortem examination in 80% of cancer patients. The prognosis was quite grim, 4-6 weeks post diagnosis. My wife is a fighter and she immediately said "I have a mutation, and these drugs

will stop it.” There were also brain mets, about four of them all 5mm or less. There was some inflammation along the spine and appeared to be some activity in the Thoracic spine.

Merita was switched to a second generation Tyrosine Kinase Inhibitor (TKI) named Alectinib known as the retail drug Alecensa. It was pending FDA approval and her local oncologist was able to get it for her via Expanded Access trial. This drug has superior CNS penetration over Xalkori and ALK patients were responding quite well to the treatment. We were so excited and relieved. Again, her response to the new drug was remarkable. The day of her first dose she was wheelchair bound. After her second dose she was able to stand again, and by day four she was walking unassisted. The LMD was in her brain and her spine, as well as on her optic nerves. After receiving Stereotactic Radiation to her optic nerve, her vision was restored to 20/20. We believed Alecensa was going to be the miracle drug. Her first brain MRI after starting Alecensa, about eight weeks later, showed the previous mets were gone, but a few others had appeared. It did this waxing and waning of mets over the next six months, but eventually they all disappeared. Her spine continued to have issues where the cancer cells were embedding in the nerve tissue and her immune system was attacking them, but in the process the immune systems response was damaging the nerves. So, MD Anderson performed radiation to the thoracic spine via stereotactic radiation and general radiation to the entire lumbar spine. It seemed to work - for a while.



My wife's run on Alecensa came to an end right at 18 months and she was switched to the newly approved Brigatinib known as the retail drug Alunbrig. This move was not the desired move as Alunbrig is considered a lateral move from Alecensa because there are substations that are resistant to both drugs. The desired drug my wife needs to be on in our opinion is Lorlatinib. It is another Pfizer drug, but has superior CNS penetration and is also known to be sensitive to the tenacious G1220R sub-mutation and many more common mutations. We are awaiting Pfizer to approve my wife for compassionate access to that medication while it is awaiting FDA approval. Lorlatinib has shown to have excellent penetration of the BBB, which proves to be needed for patients with LMD.

This is the story of just one ALKie (this is what they refer to themselves as). There are hundreds more just like Merita. Men, women, young, old, and middle aged who do not deserve this disease. These are some of their faces:



Please help support Lung Cancer Research. This is not a disease of Karma.

If you have lungs, you too can get lung cancer.

Lung Cancer affects anyone, even healthy Non-Smokers. I know because I have Stage 4 NonSmall Cell Lung Cancer! Please get checked if you have any signs or symptoms. Even though Lung Cancer has no cure I'm on a mission of getting into remission and living a long life as a Lung Cancer Survivor!

