Seventeen Candles: Thriving With Lung Cancer Since 2006

I've never written a summary of my lung cancer journey like this before, explains blogger and author Dann Wonser in his latest post.

July 24, 2023 By Dann Wonser

Something big has happened, so big that my post is longer than usual. Read a couple more paragraphs and you'll see why.

Once upon a time, I had a sore back that wouldn't go away. After weeks of no improvement, my chiropractor sent me for an X-ray. It didn't show what caused the soreness, but it did show a spot on my lungs. That spot that turned out to be lung cancer.

That was exactly seventeen years ago. Today, July 16, is my cancerversary!

The cancer was already Stage III, and the prognosis was not good. With advanced cancer and limited treatment options available in 2006, I was expected to die within months.

I had chemo, a lobectomy, and then more chemo. The "chemo sandwich" approach was revolutionary at the time, and it worked. I had no evidence of disease for another four and a half years. Genevieve and I were almost convinced that I had beat it.

But then countless spots showed up on a CT scan of my lungs. The general oncologist (whom I naïvely accepted as a replacement when my lung cancer specialist left town) didn't think it was lung cancer. We waited four more months for another scan before he recommended a biopsy, a wait I never would accept now. By that time, the spots had grown – and multiplied.

The same surgeon who did my lobectomy performed the biopsy, using the same VATS (laparoscopic) procedure. (Needle biopsies were not an option back in the dark ages.) He called me a couple weeks later and bluntly told me I had Stage IV lung cancer. He also told me not to rearrange my vacation plans to start chemo, because "quality of life is the most important thing right now." That's when I knew I was going to die. I couldn't help but start imagining my own funeral.

This was the second time my flame almost went out.

With Genevieve's help, I found a new oncologist in a different hospital system who specialized in

lung cancer. He asked if I would agree to be tested for the 49 lung cancer mutations known at that time for research purposes only, since there were only treatments for two of them, and I had already tested negative for both. I agreed, then started chemo along with Avastin, which prevents the cancer's blood vessels from growing. That bought me another eighteen months before the cancer progressed and spread to my hips. The new testing showed I did have the EGFR mutation, which we only learned by switching doctors and hospitals. I started treatment on Tarceva, the first-generation EGFR inhibitor that had just come out. But the pain in my hips was so severe that I had to use a wheelchair, so I had radiation. It killed the pain, and life was rosy again.

By the time the cancer started growing again, my lung cancer specialist had moved away, and I was assigned to a general oncologist. Apparently I hadn't learned my lesson yet, because this doctor's lack of knowledge almost killed me as well. He had no treatment suggestions other than more chemo and perhaps some radiation, but he looked defeated. Good thing I had learned about a clinical trial for a second-generation EGFR targeted therapy from a friend. I also learned that the trial was closing very soon. I had until the end of the day to get my records faxed (this was 2011) from two hospitals and two clinics. Keep in mind that medical records departments considered two weeks a rush! I pestered them several times each, and called every nurse and doctor I knew at those locations to beg them to apply pressure for me. At 5:30 that evening, I got in.

I got in for the first appointment, that is. I still needed to have the T790M mutation, which was a coin toss. I won that coin toss and got it into the trial for Tagrisso, a drug that works without progression for an average of thirteen months. I was on it six and a half years without progression.

When it grew again I found myself another clinical trial, this time for BLU-945. Unfortunately, by the time I got in, the cancer had gone wild. It progressed to my brain, my liver, and then my spine. The pain was severe and uncontrolled, which led to Walgreens treating me like a drug addict. Fluid filled my lungs and I had to sleep in a chair for four months because I couldn't breathe lying down. I flamed out of the trial in weeks. The timing was bad; I was in the early part of the dose-escalation phase and was given one-tenth of what turned out to be the therapeutic dose.

I was back to using a wheelchair, this time because I couldn't breathe enough to walk around the hospital. I fired my general oncologist and switched to a lung cancer specialist. At my first appointment she referred me for radiation to two-thirds of my spine, arranged to have the fluid in my lungs drained, referred me to palliative care, and put me on oxygen. My pain was under control within a day of seeing the palliative care doc. I was scheduled to start chemo, but my platelet count was too low so they sent me home for a week. When I returned, my platelet count was even lower. My oncologist offered me the choice between no treatment except end-of-life care, and "threading the needle," as she called it. That meant having a reduced dose of chemo and hoping it didn't kill me. I had the chemo (of course!) and within a week I started feeling a little better. I had PleurX drains implanted in both lungs, and Genevieve drained the fluid for me every other day for months. I remained on chemo plus Tagrisso for another year and a half.

When that stopped working, my oncologist immediately put my name on a waiting list for a local clinical trial and called her oncologist buddies in the top clinics in the West to find other options. I

researched trials on my own through www.clinicaltrials.gov and checked my Facebook lung cancer groups for other ideas. Dr. Sanborn and I pooled our ideas and discussed options. I was within days of scheduling an appointment in Denver to get tested for mutations to qualify me for four different trials when a spot opened in the local trial. Good thing, too. After that I went to Denver as a backup, and I didn't meet the criteria for any of the four trials. If I had started in Denver, I would have had cancer progression for five or six weeks before learning I would need to start over in another trial. The cancer might have progressed too much for me to qualify for another trial by then.

I've now been in the amivantamab trial (no other drug with it) for over five months without progression, and I'm feeling great. I'm doing daily yoga, four hours a day of yardwork on a steep slope, golfing, and walking for an hour a day up and down steep hills. Feeling good!

There has been a tremendous amount of dumb luck involved in staying alive for seventeen years when the prognosis at the time was months. There's also been a lot of self-advocacy and Genevieve's advocacy on my behalf that isn't listed here. Attitude plays a huge part, and so does being proactive and having excellent lung cancer specialists at the right times. But even more, the love and support of family and friends like you have been tremendously helpful. Most important, and the main reason I am still alive, is the love and support of Genevieve, the love of my life.

I've never written a summary of my cancer journey like this before. It feels dry since I haven't written about the joy that has come along the way. But it would take a book to write about all of the things that have made life so amazing over all these years. Speaking of…

I will be giving away FREE COPIES OF MY BOOK Second Wind: Thriving With Cancer on August 1st, which is World Lung Cancer Awareness Day. In it, I share not only what has kept me alive, but what has helped me thrive with lung cancer. I'll post a link a few days in advance.

Thank you for being part of the most extraordinary journey I could have hoped for.

This post originally appeared July 16, 2023, on Dann's Cancer Chronicles. It is republished with permission.
