

Keeping Hope: My 10-Year Journey with Cancer

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Bad News

I did not think there would be any reason to worry when I visited my physician in 2008. I had a persistent cough and some trouble breathing. The doctor attributed my symptoms to bronchitis. However, after a couple of weeks without improvement, he suggested that I get a computed tomography (CT) scan of my chest, just to make sure everything was alright. I was a little worried, but did not think of the worst.

My worrying was justified. In September 2008, a mass was found in the bronchus of my left lung. I was referred to Roswell Park Cancer Institute (RPCI) in Buffalo, New York, for further evaluation. I underwent a bronchoscopy in November. I received a devastating call after the procedure—the biopsy revealed squamous cell carcinoma *in situ*.

When I found out I had lung cancer, I was scared that I would die. I knew that I did not have the cleanest medical history, as I had been a cigarette smoker for 40 years and had been exposed to asbestos through my job. I had chronic obstructive pulmonary disease, coronary artery disease, and hypertension. However, I never imagined hearing those words, “You have cancer,” and I certainly could have never prepared for the shock that came with this news.

Quitting smoking was difficult—I was smoking 1 1/2 packs of cigarettes per day until 2006, when I first tried to quit. I was able to cut down to just 1 pack per day, but I knew that I had to completely nix the habit once I found out that I had lung cancer. It took many tries, but I eventually quit cold turkey in late 2010. I was

completely distraught facing the reality of my health. How many years did I have left? When will be the last time I see my family? Do I have any hope of surviving?

The Journey

That phone call in 2008 was not the first time I was told that I had cancer: 2 years earlier, in 2006, I was diagnosed with squamous cell carcinoma *in situ* in my mouth. The cancerous lesion on the floor of my mouth had to be surgically resected twice. Although successful, the surgery came with complications. During the healing process, I developed an infection due to problems with my left submandibular gland. I underwent mandibular surgery and the placement of a jaw prosthesis in 2007. With the resections and the prosthesis, the doctors at RPCI were able to eradicate the cancer from my mouth. Although it had been a successful process overall, the treatment did not prevent the later development of squamous cell carcinoma in my lungs, and was only the start of what I would have to endure.

In 2012, I was found to have invasive adenocarcinoma in the upper lobe of my right lung, in addition to the squamous cell carcinoma already present in the lower lobe of my left lung. The doctors and I agreed on a lobectomy to prevent the invasive cancer from spreading.

The lobectomy was only the beginning of the most difficult part of my journey with cancer. I was in utter despair when I first learned that removing part of my lung would be the best form of treatment. How

would that affect my breathing? My daily life? The things I like to do for fun?

After the lobectomy, I was hospitalized for 1 week due to pneumonia. I was released, needing to take supplemental oxygen for the next 2 months. The pneumonia came back nine more times during the next 13 months. I was hospitalized repeatedly, needing intravenous antibiotics to get better. I was totally miserable through the process—the constant sickness, hospitalization, and inability to breathe made me question whether I would ever fully recover and if cancer would end my life.

Eventually, in November of 2013, a silicone stent was placed in an airway in my right lung to improve my breathing. After the stent placement, I did not get pneumonia as often, and the amount of mucus accumulating in my lungs lessened; however, I kept getting slight fevers and often felt fatigued and achy—I just couldn’t win. At that point, I weighed only 117 pounds; I nearly lost hope about finding a cure to my cancer. It wasn’t until one day a little later, when I was thinking about all that I would lose if I died, that I knew I couldn’t give up the fight. There were too many things I wanted to do in my life to give up. I knew I was being taken care of and that my doctors were working to find the best possible treatment for me. If I had survived thus far, I would keep surviving. I had to keep hope.

The Treatments

I have enrolled in many clinical trials since my diagnosis in 2008. I started with erlotinib

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in early 2010, and when that trial ended at the end of the year, I was started on calcitriol (vitamin D). In addition to these two clinical trials, I have also received photodynamic therapy (PDT), laser therapy, chemotherapy, and brachytherapy treatments.

It was hard staying optimistic and agreeing to participate in trial after trial. Each treatment I tried seemed to work in the beginning, but the treatments were never pleasant. I generally had a bad reaction, and the cancer always came back. When I participated in the erlotinib trial, my skin peeled off so badly from a rash caused by the drug that my doctor suggested that I stop the treatment. However, I did not want to quit, because I knew that even a painful treatment like this was helping me to fight for my life, if even in the smallest way. It was sometimes exhausting, but I made myself continue to remain hopeful that each new treatment I tried would be my saving grace and cure my cancer.

Although I knew I had to keep hope to continue fighting the disease, I was still scared that I was going to die, because the cancer kept coming back. The PDT treatments I started receiving in 2009 work by treating the cancer with a photosensitive drug that kills cancer cells when activated by light. However, because the drug could end up elsewhere in my body, I had to limit my exposure to sunlight for 90 days. This was perhaps the darkest—both in the literal and figurative sense—part of my journey with cancer, and truly tested my ability to stay positive and hopeful.

The Consequences

Throughout my battle with cancer, despite many setbacks, I have mostly been able to maintain my normal life. It was saddening when I had to quit my new job as a direct care aid for adults with developmental disabilities in 2013, but I have been able to fill my time traveling and pursuing my hobbies instead. Despite having some difficulty carrying heavy bags and getting winded on stairs, I am still able to go fishing in the Pacific Northwest and visit my family in southern California from my home in Buffalo, New York.

The worst nonmedical setback I have had to deal with since my diagnosis was leaving my girlfriend of 30 years. She had

been worried about taking too much time off from work to care for me and take me to appointments. I realized that sticking with me through my battle was something she could not commit to doing for me. It was the most heartbreaking realization, but, after plenty of agonizing debates with myself, I knew I had to look out for myself and do what would be best for me in the long run. In the end, that meant choosing to leave her, setting her free, starting over, and continuing my journey by myself.

The Fight

Today, I continue to be monitored and treated for lung cancer with regular bronchial biopsies, photodynamic treatments, and bronchial cleanouts. In January 2015, I was diagnosed with basal cell carcinoma on my right jawline, but the PDT eradicated it. After almost 10 years of dealing with cancer, I am still hopeful and confident in my doctors' abilities to continue managing my cancers and helping me fight the battle.

I am thankful for my good friend, Tina, a nurse who was a coworker of mine when I worked at the developmental disabilities center. She comes to my procedures and appointments with me, answers my worried phone calls at 2:00 A.M. when I can't sleep, and more. She has been my biggest source of support outside of my family, ensuring that I do not have to fight on this journey alone.

Overall, I am only lucky and glad to be alive today. After 10 years with cancer, I have learned that keeping hope and being optimistic is one of the best ways to deal with such a life-threatening disease—without that, you have nothing with which to keep fighting. The cancer may not be gone, but neither am I—and I intend to keep winning the battle.

Physicians Perspective: Drs. Samjot Dhillon and Kassem Harris

Our pulmonary team had the first contact with Mr. Rivers when he proactively enrolled in the bimodality lung cancer screening program of RPCI in 2008. Taking into consideration the multiple risk factors, including prior head and neck cancer, significant smoking history, and severe

chronic obstructive pulmonary disease, he underwent autofluorescence bronchoscopy together with regular CT surveillance of lung nodules. We found an area of carcinoma *in situ* in the left upper lobe during his first bronchoscopy.

Mr. Rivers is a strong proponent of research to improve treatment of cancer, and he participated in a phase I trial of an investigational agent, 2-(1-hexyloxyethyl)-2-devinyl pyropheophorbide-a, with the benefit of a very short duration of photosensitivity. He had to be retreated with PDT using the standard drug, porfimer sodium. Repeat biopsies showed areas of dysplasia with no evidence of cancer. Mr. Rivers subsequently participated in two phase I clinical trials of chemoprophylaxis of lung cancer (low-dose erlotinib and high-dose calcitriol) and underwent surveillance chest CT imaging and autofluorescence bronchoscopies, per our standard protocol.

Unfortunately, almost two years after his second PDT treatment, he was found to have recurrence of carcinoma in the left upper lobe with an invasive component. We unexpectedly found an abnormal area of autofluorescence in his right upper lobe bronchus. Biopsy showed a new invasive adenocarcinoma. He underwent right upper lobectomy with sleeve resection for stage 1 lung cancer, followed by adjuvant chemotherapy and radiation treatments.

Over the following 6 months, Mr. Rivers developed recurrent episodes of pneumonia. On the basis of chest CT imaging, we made a diagnosis of right main stem bronchus stenosis. He underwent therapeutic flexible and rigid bronchoscopy, and a Dumon silicone stent was placed. His pulmonary status improved after stent placement, and the frequent episodes of pneumonia abated. The stent was removed 1 year later with no stenosis recurrence.

The left upper lobe bronchus carcinoma *in situ* recurred and spread proximally to the mid-left stem and distally to the subsegmental bronchi. Based on his improvement and a strong will to try anything and everything possible for treatment, we performed endobronchial brachytherapy for the left main stem and left upper lobe bronchi. He then underwent another endobronchial brachytherapy treatment a few months later, because of recurrence of the left lung airway cancer.

Regrettably, both brachytherapy treatments were ineffective, and the left carcinoma *in situ* recurred. This carcinoma extended from the subsegments of the left upper lobe to the left main stem with an affected area of 8 cm in length. After a multidisciplinary discussion, we decided to treat the

patient with PDT again using the porfimer sodium. The treatment was complicated by significant airway plugging and recurrent pneumonia, requiring multiple bronchoscopies for airway cleaning.

Even after all these set-backs, Mr. Rivers' health improved, and he

is now hoping to be disease free at the time of his next bronchoscopy and biopsy 2 months from now. ■

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