

## All you need is a pair of lungs to be at risk—Michelle Hills Story



Before my own lung cancer diagnosis, if someone were to ask me the odds I would be diagnosed with Stage IV Lung Cancer, I would have guessed something along the lines of one in a million. What I didn't know, along with most, is that those odds are closer to 1 in 16. Lung Cancer is the public health crisis no one is talking about because we have been taught, if you don't smoke, you won't get lung cancer. No one is looking for lung cancer in an otherwise healthy 51 year old competitive athlete.

During our "annual doctor date" in June, 2018, my husband and I met with the Primary Care Physician for a routine physical. In passing my husband mentioned I had a little cough following a sinus infection the month before. We didn't think much of it and came home with a nasal spray and cough "pearls". We were totally unprepared for what unfolded over the summer.

As a never-smoker, the pathway to an accurate diagnosis became a long and difficult one consisting of multiple visits to primary care physicians, allergists and pulmonologists. Each physician had a different diagnosis and a different treatment plan, each with the expectation of resolving a progressively worsening cough.

By August, 2018, I couldn't speak a full sentence without heaving coughing spasms. Two chest x-rays revealed an atypical pneumonia and some broken ribs. The doctors were stumped and I was referred to another specialist in infectious disease. After a dozen appointments with three different physicians, a nurse practitioner ordered a CT scan and directed me to the nearest emergency room. She suspected I had a pulmonary embolism. At this point, I had lost count of the number of suspected diagnoses. I just wanted the cough to go away. I hadn't slept through the night in months and it was getting impossible to keep up with the demands of my job as a health care executive.

As we entered the Emergency Department, I wasn't overly worried, thinking I would receive fluids and antibiotics and be on my way home within a few hours. When the physician entered the room, there were a lot of words mentioned, but the only phrase I remember was "abnormal CT scan". With a suspected viral or fungal infection, I was admitted. As the viral studies came back negative over a 24-hour period, the first pulmonologist ordered a scope of my lungs called a bronchoscopy. However, the next day another pulmonologist canceled the procedure and ordered a biopsy for the following morning. The only thing I could think of at the time was, "Gosh, I'm really hungry, when can I eat?" My food had been held for almost 24 hours in anticipation of the bronchoscopy. I was told a biopsy would be the fastest way to identify a rare fungal infection.

My husband asked the hard question: Could this be cancer? It wasn't on the top of anyone's mind. I was a never-smoker, had no family history of lung cancer and my house had a radon remediation system. The doctors were still pursuing a fungal infection diagnosis. Even the interventional radiologist said they didn't think it was cancer and believed I'd aspirated during a coughing fit. I blurted out, "you guys have no idea what you're dealing with." I am from New Jersey so sometimes my verbal filters don't work that well, especially when I am hungry.

After a successful tissue biopsy, I wanted to go home. I was receiving intravenous fluids, antibiotics and an antacid. Nothing was helping and each day I felt worse. I saw no point in remaining in the hospital to just wait for CT results. So I convinced the hospital team to let me go home and take the medications orally. I threw out the antacid, knowing there was no way I could have acid reflux disease.

Exactly 48 hours later, the phone call came. The pulmonologist said the ominous words, “you have adenocarcinoma, lung type”. I wasn’t exactly sure what that meant but it didn’t sound good. In a way, I was relieved because we were finally getting to the bottom of this horrible cough.

We went to see the pulmonologist a few hours later where he indicated I had lung cancer, probably stage III. He would organize a referral to an oncologist and recommended a course of chemotherapy. We were in shock. I began to sob. I asked about a second opinion. The pulmonologist was happy to arrange one.

Following a dizzying number of appointments, the news wasn’t getting any better: Stage IV lung cancer. The initial biopsy did not reveal any “targetable mutations”. Dr Google was a scary place; with a prognosis of 6-12 months, I didn’t see the point of treatment.

Somehow my oncologist got me comfortable with one round of chemotherapy while we waited for comprehensive biomarker testing to be completed by a specialty lab in Boston. Three weeks later, we finally had the correct diagnosis: ALK Positive Non-Small Cell Lung Cancer. This was a game changer. Rather than a course of chemotherapy, I started a targeted therapy where I take six pills a day. What could have been an imminently terminal disease turned out to be a treatable condition. My cough resolved immediately after one dose of therapy and I got the first full night of sleep in four months. Diagnosis is not prognosis.

Trying to put my life back together was equally complicated as I was unprepared for the initial response when sharing my story; the most common reaction by far was “I didn’t know you smoked”. Decades of public health initiatives have failed the primary care community. Each year over 40,000 people who have never smoked are diagnosed with a late stage lung cancer.

It took almost four years to find my tribe at The White Ribbon Project. It’s a grass roots non-profit organization committed to changing the public perception of lung cancer. It is critically important to educate the public that anyone with lung can get lung cancer and no one deserves it.