

# TRIAL OF HER LIFE

---

By Evie Boss Cogan

I had just returned from an extraordinary four months living and travelling in Europe. Our permanent home was based in Bologna, Italy, which was a remarkable springboard for other wonderful destinations. My sabbatical began with a teaching stint in Basel, Switzerland. When my teaching responsibilities ended, I took the train to Bologna. I was unable to appreciate the majestic beauty of the Swiss Alps because I felt sick, very sick. I had a terrible cough. I self-diagnosed it as a bad case of bronchitis. I was so happy and relieved when Dan (now my husband) welcomed me at the train station in Bologna. He carried my luggage (quite sizable because I packed for four months and two seasons of clothing, plus all my teaching materials). I was soon to be at my new home with my first Bologna meal. After a lot of rest and more Italian food, I began to feel myself again. The only memory of not being 100 percent was my dad's remarks when I spoke to him on the phone. "You need to check out that cough." I always agreed and after I hung up the phone gave it very little thought until our next conversation when I would agree again and so it went. I had become immune to noticing its very existence.

When I returned to the U.S., I did notice however that not only did the cough persist but that it was actually getting worse. I returned in early July 2005 and by July 21 I had my first chest X-ray. The results came back negative. Thank God. I ruled out the worst of my fears. Now it would be just a matter of getting to the root of the cause of the cough. My doctor treated it initially as allergies and put me on Claritin. A couple of weeks went by and the cough worsened. My doctor thought I should see either an ear, nose and throat specialist or a pulmonary doctor. I opted for the ear, nose and throat specialist probably because it just sounded less ominous. So I made the appointment and had lots of tests. I began to be treated for acid reflux. September came and I started my new semester of teaching Business Law at La Salle University. Lecturing became very difficult. My medication for acid

reflux was not working. They were helping as much (or as little) as the allergy meds. The specialist decided another test was in order, a CT scan. This was all new territory for me. I was a very healthy individual. I liked broccoli, I was a serious walker and I never smoked. I came from a healthy family line and had a grandmother who lived past 100.

I had the CT scan. Dan was back in Italy working when I received the voicemail from the doctor. His message was to call him back as soon as possible. From the sound of his voice I knew instantaneously that there was a problem – a serious problem. I called him as soon as I got the message. The conversation is now a blur but the words I remember were that I had fluid in the lungs. I needed to see a pulmonary specialist immediately but first I needed to pick up the X-rays and CT report. I drove to the hospital the next afternoon after work to



pick them up. I got back into my car and began driving home. At a red light, I started reading the report. The words were jarring. I would realize later that the report's conclusion would alter my life forever.

I zoomed to the bottom of the page – “Impression: Right lung carcinoma.” I could read no more. I called my son who was celebrating a Rosh Hashanah dinner at the home of his fiancé's parents. This was so uncharacteristic of me. I had always shielded him to an extreme, never wanting to burden him with what life throws one's way. But this was different from any prior experience...and Dan was away, far away.

And so began a series of doctor appointments. The first oncologist we met with told Dan and me that I should “go home and get my affairs in order.” The prognosis was bleak and she did not sugarcoat a thing. She left the room and left us there to hold each other and cry. I needed a second opinion. I found Dr. Corey Langer at Fox Chase Cancer Center (he is now at Penn). He is a wonderful doctor and person. I always leave his office feeling better and with hope. It did not take me long to figure out he was the doctor for me. My journey through chemotherapy, radiation and more chemotherapy was about to begin. It was intense and fatiguing, but I marched forward as a soldier does in battle, after all I was in the battle of my life.

The treatments beat my cancer into submission, for a time anyway. I returned to teaching and to a somewhat normal existence. I was euphoric. No more chemotherapy! I felt pretty good but was left with a great deal of permanent damage to my lungs from the radiation. I was managing my cough that was now attributed to the effects of radiation rather than the cancer. I took steroids and was fairly stable for more than two years. Life was good.

I then noticed that my cough was returning. By now I had a wonderful team of doctors. Dr. Gregory Kane, my pulmonologist at Jefferson University Hospital, was one of them. He told me at the beginning that he would be the quarterback on the team coordinating my care. He has been spectacular in that role and the person I go to when I run into a problem. Now he upped the steroids that had worked in the past to control the cough. This time the steroids did not help. More procedures and more tests. The verdict was in: my cancer had returned.

In March 2009, I began a number of different therapies. Progression of my disease continued. Nothing was really working and all the chemotherapy began to take a toll on me. My cough worsened. Sometimes it was a struggle to communicate. To help control my cough, I began taking codeine in addition to a prescribed pill. I carefully controlled the timing of my doses so I was fortified with the best weapon in my arsenal when I was in the company of family or friends. Codeine became my best friend. I was instructed to take two

to three doses a day. That worked in the beginning but soon that was not enough. I needed more of the cherry tasting syrup to be in the presence of others. I began to take it earlier in the day and more often than directed. I had no trouble justifying this: after all I have advanced lung cancer. What difference could this possibly make? I slept a great deal during this time. I was sound asleep when my friend Marilyn called and left a message that she saw a story on “World News Tonight” about a new direction in the treatment of lung cancer. When I awoke from one of my many naps I listened to her message. I Googled some keywords and found the clip. Could this be something that could help me?

Bill Schuette from Ohio was the subject of the report. He was at the end of the line with chemotherapies that were not working. His doctor had run out of ideas when Bill saw a June report on Linnea Duff, another lung cancer patient who had entered Phase I of a clinical trial at Massachusetts General Hospital (MGH) in Boston. Bill, like Linnea, qualified for the trial because they both possessed the EML4/ALK “mutation.” Within days of taking the experimental drug they both began to feel better. Just as remarkable their CT scans were extraordinary. Both had an almost complete resolution of the cancer! One thing I knew for sure...I wanted this drug. But would I qualify?

During my next visit with Dr. Langer, I mentioned the new clinical trial at MGH in Boston. He of course was aware of the clinical trial and immediately stated that I must see if I qualify for the trial. From my research, I knew it would be a long shot.

The clinical trial was sponsored by Pfizer. To qualify, I had to possess a particular gene rearrangement called EML4/ALK. Gene rearrangement is a process in cells that can contribute to the transformation of a normal cell into a cancerous one. It is found

in lung cancer tumors and a wide variety of other cancers, but not in normal cells. Gene rearrangement means that the gene is in a different place than it normally is. This altered gene is not acquired by heredity but rather from carcinogens in the environment. It is this rearrangement that drives the growth of cancer cells. The EML4/ALK genetic rearrangement is seen in about 3 to 4 percent of all the non-small cell lung cancer population. (Non-small cell lung cancer accounts for approximately 80 percent of all lung cancer cases.) The ALK rearrangement in lung cancer was discovered in the laboratory in 2007. Pfizer quickly began to develop a drug that would target the altered gene and inhibit its growth and leave healthy cells alone. This is personalized cancer treatment. There are other genetic mutations that have been identified, i.e. EGFR and K RAS and for which some targeted therapies exist. The science of identifying other altered genes is at the infancy stage and the possibility for many cancer treatments is exciting. The

My journey through chemotherapy, radiation and more chemotherapy was about to begin. It was intense and fatiguing, but I marched forward as a soldier does in battle, after all I was in the battle of my life.

drug is not a cure for cancer but rather it halts the growth of the cancer cells. But for how long, no one at this point knows.

My oncologists at Penn discovered that some of my tissue remained from the biopsy I had several months earlier. They were instrumental in getting my tissue sample up to the MGH lab in Boston. The wait began. There were so many people who saw or heard about the report that the MGH lab was flooded with tissue samples. My tissue sample had to wait its turn in line to be examined. Many like me were hopeful that they too could benefit from this new drug. As stated above only 3 to 4 percent will have this gene rearrangement: the odds however are much more favorable for those who never smoked. I remained optimistic that I would qualify. One day about a month later I received a call from Dr. Jared Weiss at Penn. He told me that MGH wanted me to call to register as a patient. He had no further information. I knew in my heart that this was going to be very good news. I felt like I had won the lottery! Sure

enough, I had the ALK rearrangement and I was going to Boston within days to take the steps necessary to start the trial. I feel so fortunate that the EML4/ALK rearrangement was discovered just in time to benefit me. I was soon to become participant No. 1 in the Phase 2 clinical trial.

I could hardly contain my excitement when I made my first trip up to Boston to get the first supply of pills. I was in awe when I had my first glimpse of these non-descript white "magic pills"...here it was, the miracle that I had prayed for. The dosing is easy, twice a day and the side effects are minimal. I was instructed to take the pills for two weeks and then schedule a return visit. During this two-week period I quickly began to feel better. I was coughing less and by the end of the first two weeks I no longer needed codeine. Feeling better was a great gift and I was so grateful to be part of the trial.

When I returned two weeks later my visit began with routine lab work. I was told in advance that this would be

a long visit. The protocol in a clinical trial is very strict. The plan was that I would have three EKGs two minutes apart. I would take my morning dose of my new supply of pills and then return two hours later for three more EKGs two minutes apart and a post-dose blood draw. However the plan was upset when the results of the initial blood draw were reviewed. My liver function tests (LFTs) were elevated. I learned this was a side effect in about 10 percent of the participants in Phase I of the trial. The anticipated long visit became a very short visit. I was sent home without the pills. I would have to wait until the LFTs came down and then I would be put on a lower dose of the drug. It took three weeks until the liver enzymes returned to acceptable levels. I eagerly journeyed up to Boston again to finally get back on the drug.

My first CT scan was scheduled three days later. I didn't know what to expect since I was off the drug more than on it. But the protocol required that I have a scan every six weeks.

The results were in. I had a 44.7

# AT JAMS, YOU FIND EXPERIENCE. KNOWLEDGE. FAIRNESS. SERVICE.

## AND AN UNSURPASSED PANEL OF NEUTRALS.



Hon. James  
Melinson (Ret.)

Hon. Diane  
Welsh (Ret.)

Hon. John  
J. Hughes (Ret.)

Jerry P.  
Roscoe, Esq.

Hon. Maria Marinari  
Sypek (Ret.)

Hon. Edward G. "Pete"  
Biester, Jr. (Ret.)

Hon. Jane Cutler  
Greenspan (Ret.)

JAMS Philadelphia Resolution Center  
1717 Arch Street Suite 381B Philadelphia, PA 19103  
215.246.9494 [www.jamsadr.com](http://www.jamsadr.com)  
Resolving Disputes Worldwide

THE RESOLUTION EXPERTS





percent reduction in two targeted lymph nodes and complete resolution in a number of other nodes. My doctors thought the results were fantastic, therefore, so did I.

I was to experience several more bumps in the road with elevated LFTs and now I'm on the lowest dose possible in the trial. Thankfully I am able to tolerate this lower dose.

The results of my second CT scan were even more remarkable. The radiologists took their measurements again and this time I was up to 59.7 percent resolution. By the third CT scan, I had a 100 percent resolution in the measured targeted nodes. There is stable disease and complete resolution in some of the other nodes that were not measured. After eight months of travel to Boston, the clinical trial opened at Penn.

I remain very optimistic about my future. I feel so lucky to be a beneficiary of this exploding area of personalized cancer treatment. My hope for a miracle in the future is here and now.

I have learned much through this journey. Here are some of my more important lessons:

- I have learned that I can share all the triumphs as well as the valleys with my beloved son. I no longer feel that I need to shield him from life's harsh realities. He has proven to be a great source of love, strength and support. This journey has strengthened our bond.
- Dan has taught me the true meaning of commitment. Ever since my earthshattering diagnosis, Dan's love and devotion has never wavered.

He has been by my side, nurturing and taking such good care during some of my darkest hours. Dan and I married just before the start of the trial. We have already been married 3 ½ years.

- Since my cancer journey began, I have married, my son has married and I have experienced the absolute joy of the birth of a grandson and a granddaughter. The lesson: There are no bounds to the joys of life. Grab them when you can.
- I have also learned that I have many truly wonderful caring family and friends. I can't imagine this journey without their vital love and support. Especially, there is my wonderful and selfless sister who has been by my side during many of my trips to Boston.
- I have learned that I have the capacity to accept things that I cannot change. I do not dwell on the past or the negative. It just wastes too much energy. I consciously stop myself when I feel myself "going there." I look forward and am an optimist at heart. I am a competitive tournament bridge player. I apply a lesson from the bridge table to my life: This is the hand I'm dealt...I'm going to play it the best that I can.

During one of my Boston visits, I recognized Linnea in the waiting room at MGH. She is the young woman highlighted in the first news report. We chatted and shared our stories with each other. It appears that after almost 20 months on Pfizer's trial drug, her cancer cells are becoming resistant to the drug. Scientists in the lab are already working

to develop a second-generation drug that may minimize the development of mutation-based drug resistance. Linnea says she is in line waiting for her next miracle. I am right behind her in line. I believe that she will find it. She is a talented writer and has a blog sharing her story of survival. She writes with the hope of educating people of the possibilities in cancer treatment. I read her blog regularly because it lets me know that I am not alone in the quest to live. She recently ended a posting with words that brought tears to my eyes. Her words and images struck a nerve deep within. She wrote:

"Perhaps I represent what advanced but managed lung cancer can look and feel like. As I get in line for another miracle, it's not so very different from running a marathon. I'm prepared both physically and mentally to go the distance, but when it gets tough, when I'm tempted to quit, I will think of all of those ahead of and behind me on this course and I will hear the shouts of encouragement from the sidelines. I will know that I'm not alone, and I will keep going. Because just over the finish line is the prize I so covet. Life, sweet life; another morning."  
Yes, life, sweet life. ■

---

*Evie Boss Cogan (ebcogan@comcast.net) retired in January 2011 from teaching Business Law at LaSalle University after 24 years in the classroom.*

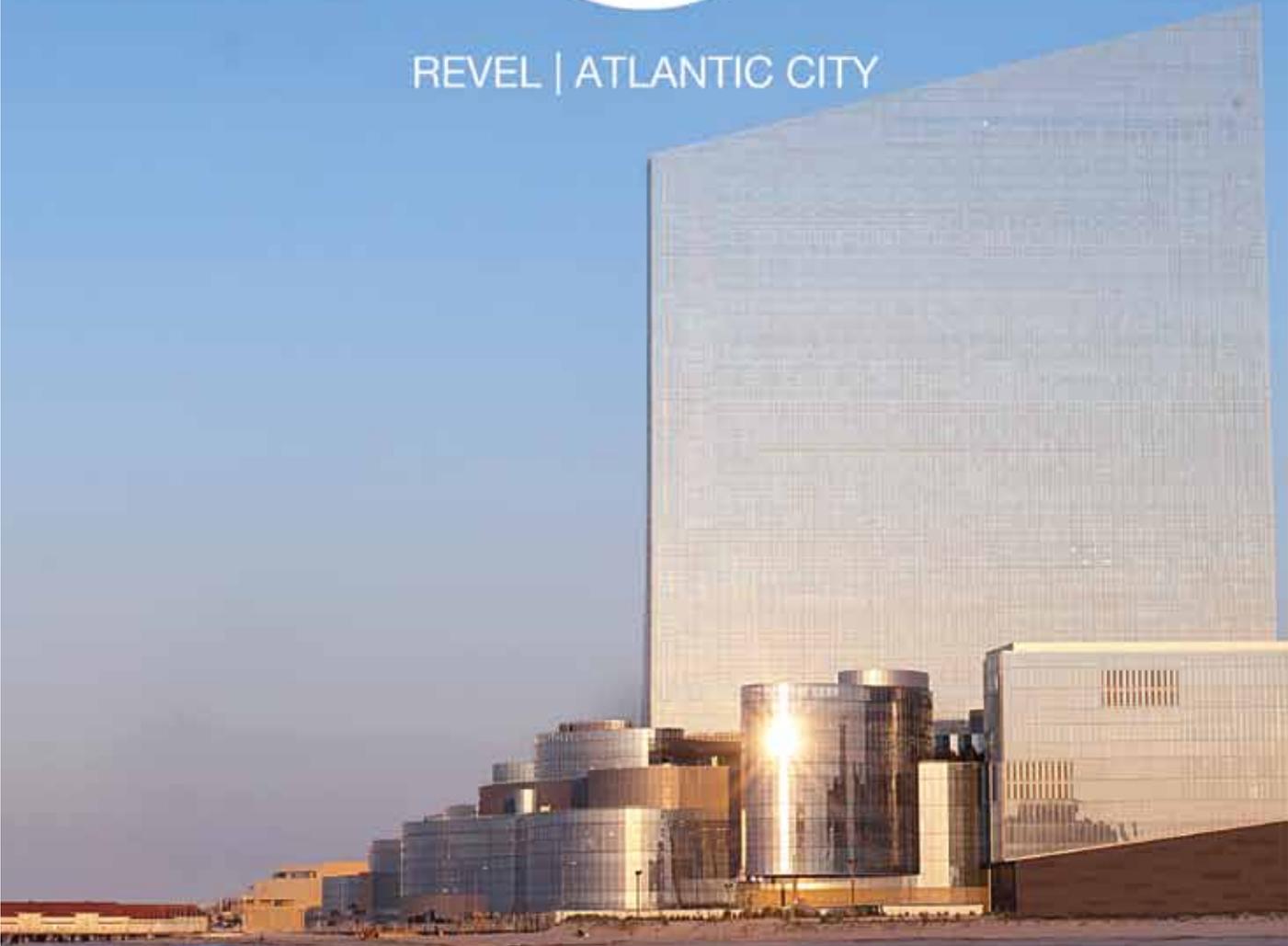
The logo features the letters 'BB' in a large, bold, blue font inside a white circle. A white horizontal bar with a thin blue border crosses the circle, containing the text 'Bench-Bar & Annual Conference' in a blue serif font. Below the bar, the year '2013' is written in a large, blue, sans-serif font.

BB

Bench-Bar & Annual Conference

2013

REVEL | ATLANTIC CITY

A photograph of the Revel Atlantic City building, a large, modern, glass-fronted skyscraper with a curved facade, situated on a beach. The building is reflected in the water in the foreground. The sky is a clear, light blue.

REGISTER TODAY AT [PHILABENCHBAR.COM](http://PHILABENCHBAR.COM)

SAVE THE DATE | OCTOBER 4-5, 2013



PHILADELPHIA  
BAR ASSOCIATION