

Developments in Lung Cancer Research; A Patient's Journey

Feldman*

Department of cancer, Chicago

***Corresponding Author:** Feldman, Department of cancer, Chicago.

Received: October 01, 2018; **Published:** October 30, 2018

I attended the International Association of Lung Cancer's (IASLC) World Conference on Lung Cancer (WCLC) in Toronto at the end of September. It is the world's largest meeting dedicated to lung cancer, attracting more than 7,000 researchers, physicians, and specialists from more than 100 countries. I was asked to give my perspective at the final press conference on what the promising new developments in lung cancer research mean to me as a patient. Below is my presentation.

I have been fighting lung cancer indirectly, and now directly, for 36 years, and most of it has been an uphill battle. I lost my dad and two grandparents to lung cancer when I was 13, and then my mom and aunt Dede died of lung cancer when I was in my 20's. I was shocked and upset that in the 14 years between my dad being diagnosed with lung cancer and my mom being diagnosed, there was not a single advancement in lung cancer treatment, despite it being the number one cancer killer. My family and I felt helpless and hopeless, and while there weren't any research on hereditary lung cancer, I knew our familial lung cancer wasn't just a coincidence.

I did what I could to get educated, be an advocate for me and my family and to help advance a cause that many were not aware of and/or not interested in. While doing so, in 2009, I was diagnosed with lung cancer at 39 years old. My kids were 6, 8, 10 and 12 - and their only association with the disease was death. They were scared, and my greatest fear was becoming a reality. I was following in my family's footsteps, and there wasn't any promising research that convinced me that the path would change.

For many years, the only distinction doctors could make was whether a person had small cell or non-small cell lung cancer, and patients had 3 treatment options; surgery, radiation, and chemotherapy. It wasn't even until the 1990s that combination therapy

was approved. And still, there was debate whether it was even worth treating lung cancer because in many cases the toxicity was worse than the disease, and the benefits from chemotherapy were marginal.

Developments in lung cancer research over the past 10 years have galvanized the community. Since 2015, the FDA has approved 23 new treatment approaches for lung cancer and as of August, there were 2,812 interventional lung cancer trials listed on clinicaltrials.gov for the United States. Driver mutations have been identified in more than 10 new genes, of which 4 already have FDA approved targeted therapies. Just a month ago, we saw an approval for immunotherapy for small cell lung cancer for patients who have progressed on chemotherapy - This was unthinkable just a few years ago.

There has been remarkable growth in the number and variety of therapeutic options. Discoveries in targeted therapies, immunotherapies, targeted radiation and better imaging have been practice changing and exciting, especially for those who have been in practice for years and can finally offer their patients promising treatment options. For me, as a patient and as an advocate for the past 17 years, I am overcome with emotion because this is the hope that lung cancer patients and our families desperately need.

I know there are always challenges, concerns, and debates, even with the most promising advancements, but the important part is knowing the science and applying it in the context of everything else that is part of being human.

My journey has been an example of that. My care team has always known that my preferences in treatment had to be guided by the impact it would have on my family and at times that has meant not following the standard of care or the traditional approach.

When I was first diagnosed 9 years I was stage I. The only reason I was stage I was because of my horrible family history I manipulated my way into having periodic scans! The only mutations that were tested for in lung cancer at the time were KRAS and EGFR, and my cancer was EGFR positive. At the time the targeted therapy Tarceva looked promising for EGFR positive patients and there was some excitement around using it for adjuvant therapy post-op in stage I surgical patients. I needed to be able to look my kids in the eyes and know I did everything in my power... so I took Tarceva as adjuvant therapy. And it worked.... until I stopped taking it.

I had a second surgery 2-1/2 years after the first to remove another EGFR positive lung cancer, but unfortunately, my follow up scan after that surgery revealed new tumor growth. I was lucky the cancer was contained to my chest, but there's only a finite amount of lung one can lose so another surgery wasn't an option. Tarceva, was still the only systemic option for EGFR positive lung cancer 5-1/2 years ago, and it wasn't even approved for first-line therapy in patients with advanced disease. There wasn't much research on using SBRT for intrapulmonary metastasis, but the risks were low, so my care team and I decided it was a better option for me than going back on Tarceva. I've been fortunate that it has worked for me for the past 5 years. And just knowing I have options for systemic therapy in the future has been mentally life-changing for me.

My dad died at 41 years old just 3 months after he was diagnosed with lung cancer, and my mom died at 54 years old just 6 months after she was diagnosed with lung cancer. I can't help but wonder (and wish) how different things would be if their cancer was caught earlier or if there had been new practice-changing developments and treatments available to them? Maybe my dad would have lived just a few more weeks to see me graduate 8th grade, or even long enough to see me graduate high school. And maybe my mom could have lived six more months and been there for the birth of my daughter, or even long enough to meet all of her grandchildren.

These are the treasured milestones that were stolen from my parents - and from me. And while early detection didn't result in a cure for me... because I was screened and because of increased awareness, a better understanding of the biology of lung cancer, advancements in research and in large part, my team taking the science and applying it to me personally, in the context of my life - last year I saw my 4th, and last, child graduate 8th grade, and this May I will see my oldest graduate college. I have had the chance to watch my kids grow up, which is something my dad didn't live to do.

There were five abstracts presented at WCLC that are exciting, promising and will be practice-changing for clinicians. But for us, patients and our families; living to see and share the important moments and milestones with our families are LIFE-changing! We MUST keep forging ahead, so others have the chance to live longer and watch their children grow up.

Volume 2 Issue 9 November 2018

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