linnea

I have been a member of this site for almost three years now, and much has changed for me in that time. Shortly before I joined, in July of 2008, I learned that the lung cancer (NSCLC, BAC) that I had been fighting since April of 2005 had spread to both lungs. I had already had a lower left lobectomy as well as chemo (cisplatin/taxotere) and was taking tarceva. It was a losing battle until a genetic test revealed that I had the ALK mutation. In October of 2008 I enrolled in a phase I clinical trial and the near miraculous happened: I had an almost total response (technically a partial response) to the trial drug (Xalkori) and began to enjoy good health again as well as a return of hope.

Update: In September of 2011 I began another phase I clinical trial for a second generation ALK inhibitor: LDK378. So far, so good.

Several years ago I began a blog to chronicle my life with lung cancer, in the hope that by describing "living" with a terminal diagnosis, I might give hope to others.

This board has been a source of support, friendship and inspiration for me, and I want in some small way to return the favor. Please check out my blog at :

http://lifeandbreath.wordpress.com/

By linnea
Reply 5113243
March 28, 2014 at 12:25 am

Jumping back into the conversation after a long hiatus. I have been on Xalkori again for 4 and 1/2 weeks. The first hurdle was receiving financial assistance as my first months supply would have been $4600 with the deductible on our insurance. My husband and I separated over six months ago and so his income no longer reflects my financial reality----it took three weeks of wrangling but I am now paying a $10 a month copay---quite a difference.

Unfortunately I don't believe I'm responding. Three weeks in I felt so bad (coughing and really, really fatigued) that I asked Dr. Shaw to prescribe an antibiotic--believing that there was likely an underlying infection. After 24 hours on the antibiotic my energy level improved and I now feel significantly better. However the cough is only getting worse and I am once again dealing with bronchorrhea in the evening. We will scan in about four weeks but the expectation is that there will be continued progression--I am in line for a slot in the PF 06463922 trial as well. Data from the lab indicates that my second acquired secondary mutation shows some significant resistance to the therapy---but we are hoping that the side effects will be tolerable so that I can eventually receive the MDT.

So---John, I shall be interested in what you have to say and whether or not your early side effects linger. Prior to your report, it sounded as if there have been few side effects noted in early participants.

Best,
Linnea

PS: from what I recall (and I could be mistaken), leptomeningeal involvement would preclude admission to the trial. Do double check that info though…I know I was initially turned away because my last therapy was chemo and not an ALK inhibitor---hence the return to Xalkori.

Linnea 是 2005 年 4 月生病，2008 年 10 月参加克唑替尼试验，并且 CR，2011 年 9 月参加 LDK378 试验，现在正在排队进 PF06463922 的实验组。

Update
Posted on April 29, 2014 | 16 Comments

I had my CT scan and appointment with Dr. Shaw yesterday. As anticipated, the news is not particularly good. The radiology report reads: ‘A mixed attenuation lesion in the left lower lung zone now measures 8.4 cm, previously 6.9 cm. There are also increased small ground glass nodules adjacent to the lesion. The central solid portion of the lesion now measures 6.2 cm, previously 4.4 cm. A mixed attenuation lesion in the anterior right upper lobe now measures 1.4 cm, previously 1.4 cm. Another right upper lobe lesion now measures 7 mm, previously 4 mm. Inferior right upper lobe mixed attenuation nodule measures 1.5 cm, previously 1.2 cm—Interval increase in size of dominant mixed attenuation lesion in the left lower lung zone and some of the right upper lobe nodules consistent with worsening lung cancer.‘

Still, were I not symptomatic, Dr. Shaw would consider leaving me on Xalkori for a little longer. However, upon examination she noted how very wheezy I am and we both agreed that it is time to try something else.

Two weeks ago I realized (with no small degree of horror) that I had gotten mixed up on my medication and had been taking my Xalkori only once a day. At most I made this mistake for two or possibly three weeks but I was absolutely mortified when I reported my discovery to Alice (Dr. Shaw). Hopefully it had no major impact upon my response, as my symptoms had never abated. However, it is a potent reminder that I have been terribly distracted. As Alice remarked, I have a lot on my plate.

I am to start the new trial on the 13th of May. We have a scheduled mediation for our impending divorce on the 16th and my first impulse was to push back the trial date. Last night I did a lot of soul searching and realized that I need to get my priorities straight (the mediation can wait if necessary).

In addition to my own worries, Pete is experiencing some challenges (kid can’t get up in the morning) and I’ve been back and forth to Exeter a number of times. Desperate times call for desperate measures, and I am setting my alarm for 7:20 every morning so that I can place a rise and shine call to my sleepy son. Yesterday I had to call repeatedly; today he picked up on the fourth ring.

I confess to feeling somewhat overwhelmed. However, my internal dialogue moves quickly from wallow to wonder; I am still here.

Live, love, life.

Moving right along, I had the lead-in dose for PF-06463922 on Tuesday, May 20th. I was in the third cohort in the dose escalation or first phase of this trial.

First dose down the hatch!

Sadie was there for the whole bloody-long day, which made it all so much more fun. She insisted that the dosing be delayed for several minutes so that it could happen right at 11:11, when I became the ninth human in the world to take PF-06463922—having been preceded by several hours by a participant in Queensland, Australia and Barcelona, Spain. What a shame that we all could not have skyped along as we dosed, although given the timezones, I would have had to have gotten up earlier!

That giddy after taste!

Anyway, this was a day I had long anticipated. And as it is already the second day of June, much has transpired since that first dose. Those of you unacquainted with clinical trials would probably like to hear a bit more about the particulars and I shall go into greater detail in a subsequent post. In the meantime I figured an update was more than necessary. To summarize: the skin biopsy was a basal cell—good news! I had my lead-in dose of PF-06463922 and regular dosing has begun. Fingers, toes, arms and legs crossed!

Linnea 的个人经历

About

My name is Linnea Duff, and I have advanced lung cancer. Over a period of 6 and 1/2 years, I have had a variety of treatments. On October 1st of 2008, I enrolled in the PF-02341066 trial (crizotinib, Xalkori). I have had a remarkable response to the trial drug, which has stopped the formerly relentless march of my cancer. The fact that I continue to survive has given me the opportunity to be a voice for lung cancer, and I felt a blog would be an excellent medium with which to tell my story.

My purpose in recounting my experiences is two-fold: to offer hope and

to provide a window into the life of someone living with terminal lung cancer. And I do mean living. I have lung cancer, but it doesn't have me. Best, Linnea

How Did I Get Here:

In two words: lung cancer. A little over six years ago, at the age of 45, I received a diagnosis of NSCLC, BAC. Prior to that moment, I thought that the only people who needed to worry about lung cancer were smokers, and I had never smoked. I also knew that survival statistics were worse than almost any other cancer: 84% of those diagnosed with lung cancer died within 5 years. The situation was not completely hopeless, as my cancer was limited to one lung. Surgery, the only accepted cure for lung cancer, was possible.

In late April of 2005 the lower lobe of my left lung was removed. This was followed 7 weeks later with adjuvant chemo (due to the size - 5 cm - of my tumor). I received 4 infusions of cisplatin/ taxotere every three weeks. This was an unbelievably difficult experience, emotionally and physically, but I was going for the cure.

However my first post chemo scan in September showed an area of "concern". The cure would elude me, although for the next two and a half years I retained a sliver of hope that the "schmutz" in my lungs was anything but cancer. Imagine yourself hoping that you have TB, or pulmonary fibrosis, or pneumonia. My cancer was the elephant in our room. However, we did our best to carry on as normal, and in the eyes of most people cancer was behind us.

By January of 2008, my cough returned and I became increasingly short of breath. And then in June of 2008, a biopsy confirmed that the cancer had metastasized and was now in both lungs. I now had stage IV, or terminal, lung cancer. In July, I began a course of Tarceva. It was known that I did not possess the EGFR mutation, which would have indicated that the Tarceva was more likely to be effective. However, there were really few viable treatment options, and Tarceva was one of the least noxious in terms of side effects. After two months a CT scan revealed that the Tarceva was having little effect. In the meantime, another genetic test had been performed on my tumor biopsy. My oncologist told me that it showed that

I possessed an ALK mutation. This was significant, because among the courses of action he now proposed was a clinical trial that targeted this mutation. My other options were to continue with the Tarceva, return to a platinum based chemo (which was previously ineffective) or, most ominously, do nothing. The clinical trial was a phase I - which means that they were testing the drugs on humans for the first time and the goal was more to assess a safe dose than to determine clinical efficacy. This was truly uncharted territory, and certainly not risk free. Definitely the old between a rock and a hard place though - if my lung cancer continued its progression, death was certain. The clinical trial offered no guarantee that it would forestall my death, and in fact, might hasten it. It was a long shot, but it was a shot.

For me this was a no-brainer. I made the decision to go for the trial. In subsequent posts, I will go into greater detail about the particulars of this journey. Let me now cut to the chase and tell you that the clinical trial was successful beyond my wildest dreams. The side effects of the trial drug were negligible for me (a rarity in the treatment of lung cancer) and within days after starting treatment, I began to feel so much better. By the time of my first scan at seven weeks, I showed an almost complete response.

My cancer is not cured, but it is being managed. I am not only still alive, but I am alive and well. What follows is a short movie that was made by Pfizer, the sponsor of the PF-02341066 trial, to be shown in house to their research team. It is as good an illustration as any of the positive impact of this drug on my family.

Why a blog? Because of the deadly toll of lung cancer, survivors who can stand up and talk about our experience are few. Survivors with stage IV lung cancer are rarer still. I have been given the gift of more time, and I would like to take this opportunity to educate and to offer insight into our experience. It is also my desire to instill hope in fellow sufferers of this awful disease. Do not give up hope. Progress has been slow, but it is coming. Genetic testing offers a world of possibilities for targeted therapy.

And now an update

Much has changed since I wrote these words. On August 26th, 2011, FDA approval was granted to PF-02341066, crizotinib, or, as it is now known, Xalkori. Hopefully stories such as mine will become much more commonplace.

After almost three years on Xalkori, I have taken my last dose (at least for now). My cancer has acquired an additional mutation which has knocked down the effectiveness of Xalkori, and I have been experiencing a slow but steady progression. On September 7th, 2011, I will have my lead in dose of LDK 378, a second generation ALK inhibitor from Novartis, yet another phase I of clinical trial.

I am hopeful that my ‘terminal’ cancer can continued to be managed; possibly for an extended period of time. I will take all of life I can get, and I think this story is far from over.

Best, Linnea