Chairman Nelson, Ranking Member Collins, Members of the Committee and staff, I want to thank you for holding this hearing on a subject that has most likely touched the lives of everyone in this room, but as I have learned over the past 18 months, you don't have a complete understanding of everything that is involved with a cancer diagnosis and prognosis until you receive one. I am grateful the Committee is taking the time to explore this issue further, and I hope I am able to add some value to the Committee's efforts.

I want to start off by saying that I hate all forms of cancer. The Committee has asked me to testify about my personal experience, so I will primarily be focusing on lung cancer, but I strongly support the funding for and the eradication of every single type of cancer.

My journey to testifying at this hearing began in the fall of 2012. I was a 31 year-old father of a wonderful two year-old boy named Joe and my wife, Sheila, was 35 weeks pregnant with our baby girl, Crosby. I was by all accounts "healthy"--there was just that nagging, blurry spot in my right eye that showed up and wouldn't go away. Since it had been a couple of years since my last eye exam, I scheduled an appointment with my eye doctor who suspected the blurriness was from a detached retina. After seeing several eye specialists and undergoing a series of tests, I was told I potentially had melanoma of the eye, but it's extremely rare for cancer to originate in an eye. Tumors in the eye are most likely a metastasis, so it was recommended I schedule an MRI and PET scan through my general practitioner.

That series of events led my wife and me back to the same doctor's office, where just a few months earlier I had passed my annual physical with flying colors, where we were told the results of the PET scan were "all lit up" and that I had cancer "everywhere"— in both of my lungs, liver, lymph nodes and bones, plus my right eye. A week later, a biopsy revealed I had non-small cell lung cancer. In just three and a half weeks, I went from seeing a blurry spot to being told I had a year, maybe two, to live, and that I was being treated for longevity and quality of life.

My wife and I were anxious to start treating the disease as soon as possible, but we were advised to wait for even further testing to be completed because within non-small cell lung cancer, genetic cell mutations can occur and selecting the proper method of treatment was essential. Further testing revealed I had a genetic cell mutation affecting less than five percent of adenocarcinoma patients called ALK translocation. On my son's third birthday, I learned I was ALK+. It's all relative these days, but we were ecstatic with this news, because in previous consultations with oncologists, we knew there was an approved and targeted "smart" drug that specifically treated this genetic cell mutation.

Despite living through it, it is still difficult for me to put into words for the Committee what that experience is like. I don't mean it makes me emotional to recall what happened during those first couple of weeks--what I mean is there are really no words to describe what it feels like to be told you have an incurable disease that will kill you. I hope and pray no one within the sound of my voice has to experience what I am failing to describe, but unfortunately, the odds are many will.

One in every 14 people will receive a lung cancer diagnosis and due to the lack of a reliable form of early detection when the disease is more treatable, lung cancer is the most lethal form of cancer regardless of gender or ethnicity. It kills more people each year than breast, colorectal, pancreatic, and prostate cancers combined. According to the National Cancer Institute, approximately 160,000 people will lose their lives to lung cancer this year. That is the equivalent of a jumbo jet falling out of the sky every single day for an entire year. The five year survival rate for lung cancer patients is only 16 percent. For stage four patients like me, the chances I live more than five years is only one percent. That means I have a one percent chance of watching either of my kids enter the first grade, much less watch them graduate from high school, walk my daughter down the aisle, grow old with my wife or hold a grandchild in my lap.

Lung cancer kills almost twice as many women as breast cancer and almost three times as many men as prostate cancer, yet the funding lung cancer receives pales in comparison in large part due to the stigma that lung cancer is self-induced as a result of smoking. This is a stigma that needs to end. I believe smoking is a terrible addiction and have never smoked myself, but lung cancer is not just a smoker's disease. We must change this perception of lung cancer in order to make more progress in combating this country's second leading cause of death. The recently passed Recalcitrant Cancer Act directing the National Cancer Institute to focus more resources on cancers with lower survival rates is an encouraging step in the right direction.

I have included a number of statistics in my testimony today, but I don't consider myself to be a statistic. I never have. In fact, my age and form of lung cancer makes me an outlier, but statistics are driven by facts and the facts are more funding is needed for lung cancer research. Research saves lives, and I am a living example of that. The drugs that have kept me alive for the past 18 months were not available just seven years ago.

The first drug I was on, Xalkori, or Crizotinib, is a "smart" oral chemo which specifically targets the ALK translocation. It proved to have immediate and dramatic results. Within a week of being on Xalkori, I had regained my energy, my vision was almost clear, I was back to work and most importantly, was present at the birth of our daughter. Within two weeks, I was exercising again. Unfortunately, after two short months, the efficacy of Xalkori played out just as dramatically, and I wound up on the operating table to have cancerous fluids drained from around my heart and both of my lungs.

Thanks to my amazing team of doctors, I was soon enrolled in a clinical trial for another oral chemotherapy, a second generation ALK inhibitor, LDK378, at Fox Chase Cancer Center in Philadelphia, PA. The average response rate to LDK is seven and half months which is approximately how long I was in the trial before I started having major complications and progression of disease. During those seven and a half months, I watched my son turn four and my daughter turn one, and my wife and I spent a week driving the Pacific Coast Highway which is

something we had always wanted to do together. LDK378, now known as Zykadia, is the same drug that received the FDA's breakthrough therapy designation last week and managed to do so within three years of the first patient being enrolled in the trial; I was one of 163 participating patients.

Unfortunately, earlier this year, the progression of disease was significant enough that in January, my oncologists moved me to straight to a non-targeted, traditional intravenous chemotherapy at Johns Hopkins which essentially poisons both healthy and unhealthy cells resulting in what can be severe and traditional side effects most commonly associated with chemotherapy. After two rounds of chemotherapy, scans revealed further progression of disease, so eight weeks ago, I began my second clinical trial, an immunotherapy trial at Johns Hopkins under the direction of my amazing oncologist, Dr. Julie Brahmer. In short, the idea of immunotherapy is to trick your body's own healthy cells into attacking the unhealthy cells. Side effects have been minimal, I have been feeling really well, and I have my first set of scans on this trial at Johns Hopkins tomorrow morning.

If you are keeping track, 18 months post-diagnosis, I am now on my fourth treatment. These targeted treatments, such as Zykadia, have allowed me to live a relatively normal and productive life. Thanks to these medical breakthroughs, I have been able to experience many quality filled days. We have enjoyed spending holidays with friends and family. I have been able to continue working full time. As a family, we have sat down at the dinner table together, have attended innumerable swim lessons, soccer and tee ball practices for my son on Saturday mornings, and have sat in a church pew together on Sunday mornings. In other words, we have stayed busy--busy LIVING with cancer.

As a late stage cancer patient, I am fully aware I am "kicking the can" so to speak. Luckily, I have honed my procrastination skills over the years, and with the right combination of science, prayer and the love and support we receive from our friends, family and even total strangers affectionately known as "Team Kennett," we fully intend to keep on kicking that can from trial to trial until one day, we can all celebrate a cure for cancer.

Again, I thank the Committee for holding this hearing and stand ready to answer any questions you may have.