

Written Testimony of Jessica Steinberg
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Testimony, Public Hearing
HRC 17

I stand before you, representing an emerging trend in lung cancer: diagnosis in non-smokers under the age of 45. If you have a set of lungs, you are at risk for lung cancer. Lung cancer is the nation's leading cause of cancer deaths for both men and women – this year, lung cancer will claim more lives than breast, prostate, colon, liver, kidney and melanoma cancers – COMBINED. It will kill more than 160,000 Americans this year. An estimated 60% of new lung cancer diagnoses will be in non-smokers - a combination of 45-50% former smokers (many who quit 10, 20, even 30 years prior to the onset of lung cancer) and 15% people who have never smoked. It is time for us to end the stigma associated with lung cancer and make sure that it is recognized as the public health priority that it is. It is baffling to me how often I am asked if I was a smoker when people learn of my diagnosis. I doubt anyone would ask a colon cancer patient if they always got enough fiber, or a breast cancer patient if they always did their self-exams. Yet, somehow, lung cancer stigmatizes its victims. Lung cancer is therefore enshrouded in guilt, both for the victims and family members. The bottom line is no one deserves cancer, any cancer, regardless of personal behaviors or habits. All cancers are the direct result of three things ... genetics, environment and behavior. If someone is ill, don't they deserve all of our know-how, research and talent to save them and allow them to live a productive life? Lung cancer patients seems to be the exception – when it comes to victims of this disease, society still plays the blame game. Lung cancer stands alone in that the prognosis for this disease in 2009 is the same as it was almost 40 years ago.

I was 39 when I was diagnosed, quite by accident. I had no real symptoms, except I noticed in my marathon training I was having a great deal of trouble on the hills. Never did it cross my mind that I could have lung cancer – I thought I only needed

to train harder. It was actually on this date, April 22nd, 2 years ago in 2011, that I was the victim of a serious assault. Ironically, it probably saved my life. I had a chest x-ray for broken ribs that detected a mass in my lungs. One week later, on April 29th, 2011, I was diagnosed with what was believed to be a Stage 1 localized tumor. I had a major cardio-thoracic surgery to remove a lung lobe, and during the surgery it was discovered that the cancer was much more advanced than thought. Given my age and overall good health, and that I am a single mother to two young boys, it was decided to initiate the strongest protocol possible. I had concurrent chemotherapy with chest radiation. I was incredibly sick and burned by the treatment. Unfortunately, the cancer only progressed and metastasized to my brain. I went through whole brain radiation and tried another chemotherapy. I got worse, and the cancer spread to my bones. I refused to give up – determined to raise my boys to adulthood. It was at that point that it was discovered I had a molecular biomarker of Anaplastic Lymphoma Kinase, known as ALK. This change occurs in up to 5% of non-small-cell lung cancers. In July 2012, a target therapy for the ALK mutation was approved by the FDA. I started it in December 2012, and at my scan a month ago, I learned the incredible news that no measurable cancer was detected. Stage 4 cancer is considered incurable, and the hard reality is even with medical miracles such as mine, the cancer often returns. It is my hope that by increasing recognition of the issue of lung cancer we will also increase the survival rate. Despite the fact that lung cancer is the leading cause of cancer deaths in the United States it remains the most under-funded and under-researched cancer. I hope that the passage of this bill is the beginning of bringing lung cancer into the spotlight. Right now, lung cancer is the forgotten cancer. Because of a 5-year survival rate of only 15%, there are few survivors to stand up and speak out in support of the disease – this is why it's so important for me to tell my story. I don't want anyone else to feel hopeless or feel as if they have no recourse because of no treatment options or a cure for this disease.

Thank you for your time and attention, and support of this incredibly important bill.

I know my children thank you, too.