

Social Security Administration
Compassionate Allowance Outreach Hearing on Cancers
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Commissioner Astrue, fellow panel members and guests:

I am honored to have the opportunity to speak with you today.

My cancer story begins in May of 2002 when I found a large lump on my left breast. The process of diagnosis was routine and fast; an office visit, a mammogram, an ultrasound, and then the bad news. I was 38 and very frightened. I had a job I enjoyed and lived in a neighborhood that I loved.

Within two weeks of my diagnosis I had a mastectomy and was staged at 2b, which means that my tumor was close to 5 cm and there were four out of 18 lymph nodes involved.

Approximately two weeks after surgery, I received eight cycles of ACT (Adriamycin, Cytoxan, and Taxol) adjuvant chemotherapy every two weeks, with some weeks off.

Roughly four to six hours after every treatment I would become violently ill. The good news is that the assault only lasted about a half hour, after which I would sleep. I lost my hair almost immediately and remained mildly nauseated the entire six or seven months of chemotherapy. I was achy, ill tempered, weepy, angry, and scared. I had difficulty sleeping at night. I lacked the stamina I once had. I got out of breath quickly and perspired profusely. In addition, I gained 30 pounds.

After completing chemotherapy, I received 30 to 35 radiation treatments, every day of the week with the weekends off. My body felt as if it was on a grill - I felt the burn all the way through.

In August of 2004 it was determined that my cancer had metastasized to my liver and surgery was not an option. I started chemo right away. I received Gemzar and Carboplatin for about six months. The tumors didn't change, but my markers went down.

In February of 2005 my chemo was changed to Abraxane, which I have been on ever since. The Abraxane shrunk the tumors and my markers remain steady.

Feeling sick and exhausted all the time, I could not work, and convinced that I only had 8 months to live, I left work for good in August of 2004. I started receiving Social Security in March of 2005. Although my experience with the Social Security Administration was very good, it took a little more than seven months to get my check. At the beginning, I was overwhelmed and unsure how to fill out the disability application. I made an

appointment at my local SSA office and was helped by one of the agents. We filled out the application together, and I left with a better understanding of the process and what I could expect from the disability benefits. When I've called for help, I've been helped by courteous, knowledgeable people.

The Social Security benefits are my income. They give me some independence and for that I am grateful, as I struggle daily with exhaustion and "chemo brain." The time I waited to learn if I would get benefits was especially hard. Treatment for cancer and fear of death are awful enough, but facing all of that without knowing what money you will have makes it even harder—could I afford my treatment and where I lived?

I don't know who or what agency can do much about the following, but I want to express it just the same. When a person becomes disabled, they receive roughly 60% of their last salary. That assumes 40% of their financial responsibilities are forgiven. The fact is financial responsibilities increase after diagnosis with additional insurance premiums, co-pays and prescriptions. The effect of trying to make 60 cents into a dollar leaves one feeling doubly punished, first by your illness and then by a serious lack of money. It really would have helped a lot if I could have gotten Medicare sooner. You know there's a two year wait before you're eligible, and during that time I had to scramble to pay for COBRA. For a cancer patient, that's a long time and a lot to worry about.

Thank you.