



**Susan delivering her address to over 500 conference attendees in Orlando, Florida.**

## **Society for Neuro-Oncology Annual Meeting**

**November 18, 2006**

I would like to thank Dr. Guha and the staff at the Society for Neuro-Oncology for giving me the chance to speak. Over the last twelve years I have had the opportunity to talk to a lot of doctors. But they weren't always in the same room at the same time like tonight. So it's a little overwhelming.

You've probably heard many stories like mine before. But I'd like to tell you my story, so that you're reminded of why you've chosen the career path you have. I've known Rick for over fifty years. For forty of those fifty years everything was great. We went to junior and senior high school together. I was the class salutatorian, Rick wasn't. Then we both graduated from colleges in Claremont, California. I attended Pomona. Rick was at Harvey Mudd. We married shortly after graduation and raised three children together.

By the early 1990s our children were off to college. Things were settling down. But I was still busy with volunteer work, church, and the usual things that women do to keep engaged with life. And Rick was seeing the real results of almost fifteen years of building a company from next to nothing to an international corporation. Life was good. Probably not too different from the lives many of you have right now.

Then in June of 1994, Rick and I had our world change forever. Overnight, I lost my short-term memory. I was confused and nauseated. I lost my balance. I didn't know what was happening to me. At first, the doctors at Mayo Clinic thought I'd had a stroke. But after almost four months of testing and waiting I got even worse news. I have a Grade 3 Astrocytoma. The odds then were that I wouldn't be on this earth longer than about eighteen months.

But after an experimental treatment protocol of radiation and chemotherapy a miracle happened, I lived. And I'm standing here today in front of you twelve years after that dreadful diagnosis. I'm not sure what the odds are of this happening. Rick calls me the lone data point on the far end of the bell curve. I'm not sure what that means. But I suspect it means there aren't many others who have made it as long as I have.

My survival comes with a penalty, however. I'm sure most of you are well acquainted with my kind of slow speech, slow movement, and confusion that comes from cancer and its treatment. So it should be no surprise to you to know that the most devastating thing about this disease is that it has changed who I am. I am no longer positive and confident. I can't perform many of the tasks I used to take for granted- like cooking meals. I am at a loss in a social situation. In short, I am no longer the Susan Sontag I used to see in the mirror for all the years before this happened.

It has been very difficult adjusting to my new persona. I remember when I was competent. I remember when I was strong. And I remember how I could manage my life and the lives of my three children with ease. It makes me sad that I am no longer that person. So when you leave and go back to your clinics and labs and have a bad day and need some motivation to get over that next hurdle, think of me. Or think of you or your spouse facing the situation I now face. It should reassure you that you made the right career choice. And maybe, just maybe, it will provide that spark you need to find the cause and a potential cure for this devastating disease.

Susan T. Sontag