

**STATEMENT OF JOYCE SIMONS
NEW CITY, NEW YORK
For**

**SOCIAL SECURITY ADMINISTRATION'S COMPASSIONATE
ALLOWANCE INITIATIVE HEARING ON
YOUNGER-ONSET ALZHEIMER'S DISEASE AND OTHER DEMENTIA**

JULY 29, 2009

Good afternoon, Commissioner Astrue, other social security officials and distinguished guests. It is an honor for me to be here with you today. My name is Joyce Simons and I am one of the 5.3 million Americans living with Alzheimer's disease. I am one of the large numbers of people under the age of 65 with Alzheimer's disease or a related dementia – whose world has been turned upside down.

I am a wife, a mother, a sister and one of the growing number of individuals struggling to confront the challenges Alzheimer's brings to one's doorstep - or more importantly what it steals away. This disease has had a profound effect on me, my husband of 31 years, my son and daughter and my extended family. It also ended my professional life. More than a job, more than a career – teaching, helping to shape young minds, was my greatest passion. Education had been my life's work for 30 years.

Until I left teaching in September 2007, I had been Dean of Academic Support Services and a Professor in the School of Education at Nyack College in New York. For more than a decade, I supervised programs that helped students with learning disabilities or challenges; students who were underprepared for dealing with the rigors of college life. I was responsible for helping these students become more skilled and adept at managing college level work. I supervised a staff of 20 people, and together we helped these students thrive, learn, and flourish academically. In the Academic and Support Services department, the students honed their reading and writing skills while building a foundation for lifelong learning. How could anyone not love work like that?

I was a dynamo with a lot of energy and great enthusiasm for my students. I had a fantastic family and an active and engaged social life. I was happy and fulfilled. At 54-years-old, I was no stranger to health issues. For years, I had managed diabetes, hypertension and a pituitary tumor, but I was able to balance family, health and work; until the fall of 2006, when I suffered a stroke. It was during my recovery that I started to experience memory and perception problems which persisted over time.

The signs began quietly enough, but soon became too difficult to deny. I would be in the middle of giving a lecture - sharing material I knew like the back of my hand with my students – and I would completely lose my train of thought and find myself unable to continue. I'd forget how to spell simple words and put sentences together. It would take me an hour to craft an email that once took me 2 minutes

to write. I knew what I wanted to say and yet I couldn't articulate my thoughts. Each day brought on a whole new set of challenges, even though I was doing the same activities I had been doing for 30 years – and had been doing well.

I started having problems with movement. I began to fall down a lot and lose my balance. Initially my husband would joke with me that I had always been clumsy – but as it began to happen more and more – we both became concerned.

I know the people I worked with noticed things weren't quite right. I worked most closely with my assistant and she would see and correct all of the errors I would have in my presentations and in my correspondence. My co-workers would witness conversations I would have with others and would be amazed when I would repeat these conversations and leave out major parts. Not because I hadn't heard them, but because I couldn't remember them. I began to rely on power point when giving presentations because it provided a way to focus on images and take the focus off me and the speech problems I was experiencing.

As I grew more and more concerned about what was happening to me, I also lived in fear of what it *could* be. I really can't tell you how frightening it is to know the words and knowledge and yet be unable to express them. I had a natural talent of connecting with my students and bringing out the best in them but it became harder for me when I could no longer tap into the best of myself - despite my two Masters Degrees and a Ph.D. After several months, it got to the point where I had no choice but to find out what was going on. My husband and I sought medical help and my doctor recommended I see a neurologist. In February 2007, the neurologist told me I had Pick's disease. Upon learning my diagnosis, I began to participate in a support group run by the Alzheimer's Association. When I shared my diagnosis with my coordinator, she thought based on everything that I shared with her that perhaps it wasn't Pick's disease but Alzheimer's. No one in my family has had Alzheimer's or Pick's disease. But that spring, I sought another opinion at Columbia University and learned it was mixed Alzheimer's and vascular dementia.

Armed with this information, I knew that I had no choice but to end my 30 year teaching career. Teaching was all that I had ever known. After I left work in September 2007, I applied for short term disability with my employer the next month. I went online to try to complete the paperwork for Social Security benefits but for someone who has cognitive impairment – it is way too much information to process. My husband and I went to my local Social Security office to complete the paperwork, and there was quite a lot of paperwork to fill out. But the woman who worked there helped us tremendously. I have to admit, given the whirlwind I had experienced – leaving my job the month before and coming to terms with what leaving that job would do to my family financially and as well as for me personally – I do believe that God only gives you what you can bear. I'm so thankful that I had a positive experience trying to get my disability benefits which I received five months after I applied – otherwise I don't know how I would have been able to cope.

The financial implication of this disease has been devastating for my family. My husband Rene, who is an engineer for Amtrak, was two years away from retirement. But now because we went from two-income household to a one-income household – he has to continue to work. Fortunately, my daughter is completing her Master's degree and my son is in his last year at Morgan State. I don't know how we would have been able to pay for their education, manage our household expenses and deal with the mounting medical expenses of my care otherwise.

This disease has forever changed my life – my children see that Mom looks the same and yet things are still very different. I have a tremendous support network – of family and my sorority sisters – so I'm rarely alone, and even then, someone's always calling to check on me. I can't drive anymore. I tried taking the bus, but I just get too confused. And the subway, well, forget about that, it's not even a possibility. My family and my sorority sisters take me anywhere I have to go, and I am so thankful for that. I have my black book which I write in constantly and keep track of the different medical appointments and other commitments. But I will say one of the most challenging aspects of having Alzheimer's was having to end a career that I loved.

Simply being unable to do what you've always been able to do – it truly is one of the most tragic consequences. There's nothing more I would love to do than to be back in the classroom, working with my students, helping them to walk in their potential – but with this disease, it's impossible. You can't process new information, learn new tasks and even remember things that used to come naturally. This is a disease that should be included under Social Security's Compassionate Allowance initiative – it simply is the right thing to do.

I would like to thank my husband Rene, for standing by me throughout this whole ordeal – he's been my rock. I'd also like to thank the Social Security Administration for considering this very important issue. I would also like to express my appreciation for the Alzheimer's Association for giving me the opportunity to share my story with you today.

Thank you all.