

STATEMENT OF JAY AND LAURA JONES
LIGHTHOUSE POINT, FLORIDA
for

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

JULY 29, 2009

Jay Jones: Good afternoon, Commissioner Astrue, other social security officials and distinguished guests. I am Jay Jones and this is my wife, Laura. We are honored to be here today to share our story with you - a story that includes a 3-year search that ended with an Alzheimer's diagnosis – quite a shocking discovery for someone 49 years old. It meant the end of a successful professional career for me, visits to more than 20 different types of medical professionals and specialists – neurologists, psychologists, internists – you name it, more than \$30,000 of our own money spent trying to find answers, countless hours in doctor's offices, and quite a few hours spent in our local Social Security office as well. This journey has taken a toll on our lives, marriage, family and both of our professional lives – but throughout it all, Laura has remained by my side.

Laura Jones: Yesterday we celebrated our 9th wedding anniversary and we have experienced the ups and the downs. Four years ago, Jay was entering his 22nd year as President of a very successful yacht brokerage business. For 30 years, he helped to build and grow the 20-million dollar family business. A natural born salesman, Jay truly knew the ins and outs and every aspect of the business and it was a labor of love.

I think it was actually me who first began to notice something wasn't quite right with Jay. I noticed he was a lot more forgetful, he would lose things constantly, and he just didn't seem like the person I married. He also began experiencing profound personality changes. When I brought these things to his attention, he just dismissed them or ignored them. When we would go to see his doctor, he dismissed it as well – our family doctor said stress was to blame even after testing that showed poor results – still no one believed that there was anything wrong with Jay. I mean he looks incredible – he's physically fit, but I knew there was something more serious going on. I just felt it in my gut.

Jay Jones:
I began to suspect there might be a problem when I kept losing things and forgetting how to get to places that I had been going to for years. I began to rely more heavily on taking notes while at work. I took copious notes to help me remember things. I know that the people I worked with had to have noticed eventually I wasn't keeping up with things like I used to – but I was the President

and I'm sure they didn't feel comfortable sharing whatever concerns they may have had with me.

Laura Jones:

His math skills were some of the first skills to go for his job. As a salesman working with figures, percentages, and managing million dollar deals mathematical errors were very serious. I hired a math tutor to try to help him, but it didn't help. He tried to keep up in meetings, but had more and more difficulty keeping up with the others. From 2003 until about 2006, it was a very challenging time for us as we sought out a definitive diagnosis and tried to pinpoint what the exact problem was. There's no history of Alzheimer's disease in Jay's family, and especially in younger people, I guess doctors tend to want to rule everything else out, before they say Alzheimer's. One consideration was gastro-intestinal cancer, which, we were told, sometimes causes cognitive impairment. Eventually we learned it was something that HAD NEVER OCCURRED TO EITHER OF US— Alzheimer's.

A short time after we learned that Jay had younger-onset Alzheimer's disease, we told his business partners and they wanted him out immediately. It turned very ugly and eventually the company was dissolved then reorganized in order to remove Jay.

Jay Jones: That was a tremendous blow because I really did put my all – blood, sweat and tears into building the organization and this really took a toll on me and these long held relationships. It was especially hard as my former business partners proceeded to share my Alzheimer diagnosis with others in our business – really sabotaging any hope I had of getting work in the yacht sales business again.

Laura Jones: But the truth of the matter is, he couldn't work any longer. It was impossible to learn any new skills and he had a hard enough time remembering the things he once knew. He tried working for a friend and business associate of 20 years. This man knew about Jay's Alzheimer's and was very compassionate, but there were so many nuances that Jay just couldn't get, so that job never even got off the ground. After that, we tried to think of other things Jay could do, but he couldn't learn any new skills, so it would have been impossible for him to function in a new job.

After Jay was removed from his first job, in 2007, he had no benefits at all, and we filed for disability benefits. I filled out the paperwork for Jay and went to the Social Security office. I will say that this was one of the most challenging times for me. Our world had been turned upside down, I had to plan to return to work to support us, we had a four-year-old daughter to raise and it was just so much. I went down to the Social Security office to file the paperwork; I had all of our documentation from the past several years – our paper trail of diagnosis. I admit it really was challenging because I was in such an emotional state. But I still felt

like we presented a strong enough case. Even the person from Social Security who helped me with the paperwork thought we did it right. I can't even imagine how someone who is cognitively impaired is supposed to be able to fill out all of the paperwork, but again I thought, despite everything, we completed the paperwork successfully. Imagine our surprise, when 6 months later, we got Jay's denial letter.

Jay Jones: It really was a shock. We had visited a number of doctors over two years – including the head of neurology at the Mayo Clinic – and had numerous medical reports that documented my condition. But because the reports were older than 6 months, they were not accepted. In fact, all the documentation we had from the past four years which showed the progression of the disease was not considered because it had not been conducted in the past 6 months. Instead, we were referred to yet another physician by Social Security. In the final report, this physician wrote little about my dementia, and instead wrote that I was “eccentric” and “effeminate”. I felt that our proof was overwhelming, but yet again, we were denied. Laura immediately went out and got an attorney and we filed for reconsideration.

Laura Jones: The process of trying to get a diagnosis coupled with trying to secure disability benefits was exhausting and overwhelming – an unimaginable ordeal. We were living off of our savings, I had returned to work – pretty much just to get the health insurance. With all of the challenges we had to endure to get a diagnosis, then to try to get disability benefits – it was quite a difficult time. Eventually it took more than 12 months to get approved and then only after we had hired an attorney to help us, who as per social security rules is awarded 25% of the past benefit, in our case more than \$5000. I can't imagine what it's like for those who don't have the financial means to survive the wait. As part of the reconsideration process, Jay was told to go to the same doctor who had originally said he was eccentric. I called the attorney who was furious and requested a different doctor which we were granted. The new doctor paid very close attention and listened to everything we had to say, she requested additional records and this time, we were approved. And here I was trying to manage and handle the new responsibilities I was facing and not knowing what to ask or who to ask --- that's the situation that I'm afraid too many caregivers may find themselves in.

Jay Jones: To get this terrible disease and have to explain to so many people that you simply can't do what you've always been able to. Believe me; I would like nothing better than to be able to work and to continue doing what I love to do. With Alzheimer's you just can't. You can't do what you used to do – can't remember old things, can't learn new things and suddenly all things you know become unfamiliar. It was hard for me because people look at me and see a healthy young 52-year old man who is physically fit and yet this disease invades your mind – it truly robs you of your livelihood.

Laura Jones: If I had to give any advice to someone who was going to apply for Social Security disability, I would tell them to get \$300 or \$400 and hire an attorney to guide them through the initial paperwork process because it's too overwhelming and complicated to do on one's own.

We would like to thank all of you for listening to us and certainly for considering this disease under the Compassionate Allowance initiative. We hope that by sharing with you our story and the ordeal that we faced – you will do what you can to ensure it's not the experience that others have.

We also would like to thank the Alzheimer's Association for giving us the opportunity to speak with you today and specifically the Early Stage Advisory Group for embracing us and letting us know we aren't alone.

Jay Jones: Thank you all very much.