

**Statement of Chuck Jackson  
Albany, Oregon**

**U.S. Senate Special Committee on Aging  
May 14, 2008**

Good morning Chairman Kohl, Ranking Member Smith and other distinguished guests. It is my honor to be here. My name is Chuck Jackson and I live in Albany, Oregon. I represent one of the hundreds of thousands of people in the United States with early-onset Alzheimer's disease. So far seventeen of my relatives have lost their battle with the disease – most before the age of 65. I am now living with Alzheimer's as is my older brother Danny, age 60, and three of my cousins.

More than 20 years ago my Aunt Esther testified at one of the very first Alzheimer's hearings held in Congress. Unfortunately, former President Ronald Reagan later vetoed legislation that would have increased funding for Alzheimer research and provided programs to help caregivers - leaving the problems and challenges of Alzheimer's to be faced by later generations. At the time of my Aunt Esther's testimony I was working for Burlington-Northern Railroad in Montana and was unable to attend the hearing. I am here today to ask that you increase funding for Alzheimer's research and finish the work that my Aunt Esther started two decades ago.

My experience with Alzheimer's started in 1967 when I was 13 years old. I became a caregiver for my mother Rachel who had started to exhibit symptoms of the "family disease" at the age of only 44. She died of Alzheimer's in 1973 at age 50.

My personal experience with Alzheimer's began in May of 2004 when I received a telephone call from my brother Danny who had already been diagnosed and was participating in a clinical trial at the Baylor College of Medicine in Texas. The trial was testing a combination of Alzheimer medications – similar to the cocktail therapy that had been developed for HIV/AIDS – and achieving good results. The researcher suggested that my brother tell other family members who knew they carried the Alzheimer gene to begin the combination therapy. I had learned in 2000 that I have a gene that would give me a 98% chance of getting Alzheimer's. I immediately went to my doctor to begin the process of getting on the cocktail medications.

Three months later, in August 2004, I received a bad performance evaluation at work. At the time I was employed by the Community Services Consortium in Corvallis, Oregon as an Employment Specialist helping laid-off workers find new careers. In my 14-year history with the Community Services Consortium, I had consistently received excellent reviews, scoring between 95 and 97 percent. However, in this meeting my supervisors informed me that my score was 75% and I was presented with a list of failures, including memory problems, poor organization skills, difficulty with speech and behavioral problems on the job. In a more comedic incident, I once came to work wearing one black and one brown shoe. Asked to go home and change, I came back to the office wearing the **other** black shoe and brown shoe which really annoyed my supervisor.

I was told that I had three weeks to improve my performance or I would be fired. Much of my work related to meeting people and establishing relationships with local businesses so that they

would hire the laid-off workers I was assisting. As a former AFL-CIO employee who had also experienced being laid-off, I had a strong desire to see others succeed and good people skills, which made the results of the job evaluation out of character and quite abnormal.

I immediately went to see my doctor. I told him about my poor job performance, that I had been having trouble with my vocabulary – forgetting words and not being able to find the correct words when I was speaking to people. I had also been experiencing problems with muscle control, my arms and legs would randomly go into spasms, and I was falling at times for no apparent reason. My doctor said that Alzheimer's had probably already begun to affect my brain and advised that I apply for disability benefits immediately. I returned to work the same day and completed the disability application. That was my final act at the Community Services Consortium. I was 50 years old.

Now at age 54, I'm on Medicare and receive disability benefits through CSC, my former employer, who has a private policy that pays 60 percent of my former salary. I also receive benefits from the Oregon Public Employees Retirement Fund. Though I am still living in my community and driving, I require the assistance of my former wife, Marianne, and daughter, Rachel, for some everyday needs. It is my goal to inform the American public and policymakers in Washington about the challenges of living with Alzheimer's. Focusing on the changes that need to happen to provide services and care for the growing population of younger individuals with Alzheimer's, I am an advocate for expanded services and more funding for research on early-onset Alzheimer's. I established and continue to lead a monthly Early Stage Support Group in Corvallis.

I have participated in numerous research studies including the "Pittsburgh Compound B" study led by Dr. Steve DeKosky and Dr. William Klunk. Federal funding is critical for studies like this that could potentially provide answers not only to those with early-onset Alzheimer's, like me, my brother, and cousins, but also for millions of other people facing the challenges of this debilitating illness. Unfortunately funding for Alzheimer research has declined every year for the last four years. Good scientific ideas are not being researched, young scientists and their new ideas are not being funded and life-saving treatments are being delayed or potentially lost forever. I can't understand why Congress is cutting back on funding for research when the costs of the disease and the number of people affected are going through the roof.

It is imperative that Congress increase the federal commitment to Alzheimer research now because I want to be an Alzheimer survivor – much like the breast cancer survivors who are alive today because of advances in cancer research and treatment. Otherwise my daughter Rachel or someone else from our family or even someone from another family will be back here in a few years, sitting in this same chair, making the same plea. History does not – and should not – have to repeat itself. As a country, we can do better.

Thank you again for giving me the opportunity to speak to you today.