

**STATEMENT OF -----**

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-----, IOWA

for

**SOCIAL SECURITY ADMINISTRATION'S COMPASSIONATE ALLOWANCE  
INITIATIVE HEARING ON**

**YOUNGER-ONSET ALZHEIMER'S DISEASE AND OTHER DEMENTIA**

**JULY 29, 2009**

My name is -----, I'm 44 years old and I'm from -----, Iowa. Two years ago, at the age of 42, I was diagnosed in ----- as having early-onset Alzheimer's, although we believe I might have been having symptoms of this as early as my late 30's.

Apparently this is due to a genetic defect on my late father's side of the family in which amyloid is deposited incorrectly into the brain and ultimately causes early-onset Alzheimer's. Thirteen members in the last five generations of my most immediate family on my father's side have been affected and have died of this disorder-more family members further out on our genetic family tree may have also been affected, but we haven't been able to track them at this time.

Because of the decline of my memory and cognitive abilities, I was forced to resign in 2007 from a job I loved as a chemist at ----- . Fortunately I had taken out a disability insurance policy through my employer at the beginning of my employment and was able to live on this for a time. Later, I was urged to apply for Social Security disability when it became apparent that I could never return to work or do any work – no matter how small – that would offer gainful employment. With my mother's help, we filled out the extensive paperwork only to be turned down. We were

told that they had looked at all my medical tests, genetic tests and Dr's reports and that they completely believed that I had this disorder but wasn't helpless enough yet.

Time passed, my condition grew worse and we reapplied filling out more forms with a lawyer's help who had been trained in disability law. This time Social Security disability was granted and my first disability was issued July 15<sup>th</sup> this year.

At the recommendation of one of my neurologists, we tried to get me enrolled in several different clinical trials with one medicine in particular that appeared very promising in stopping the genetic damage being done in my family. Although the medicines being tested in clinical trials were to stop or slow early-onset Alzheimer's, all the drug companies refused to accept me in any of the programs saying I was "too young" and that I had to be 50 years old in order to participate in their programs.

My Mother, who is 73 and not in the best of health, wrote this statement with some verbal input from me. She and my step-father are my advocates and help me in many, many ways, so I'm lucky but they will not always be with me.

But for all the victims suffering from early-onset Alzheimer's who are alone and aren't fortunate enough to have a spouse or parent to help them financially or to help them fill out enormous amounts of forms and paperwork, I want to act as their advocate, and urgently request that early-onset Alzheimer's disease be included in the Compassionate Allowance Initiative program. Receiving Medicare benefits earlier would allow many of these patients to stay in their own homes or apartments longer and to remain independent for a much longer period of time. Thank you.