

STATEMENT OF -----

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-----, OKLAHOMA
for

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

JULY 29, 2009

I am a professional who works with people with Alzheimer's disease and have over 15 years experience in the field. For eight years I was a certified clinical research coordinator for Alzheimer's trials and since 2002 I have been the ----- for the unique program initiated by the ----- chapter of the ----- . While the symptoms and the disease are similar in all persons affected by it, these young people in their 30's, 40's, and 50's have to deal with several unique issues. They are either just getting established or reaching their career peaks when suddenly they are confronted with a diagnosis of an incurable, fatal disease which devastates them both financially and emotionally.

Over 420 family units are included in the nationwide communication network, which we have established and maintain. I have met many of these people face-to-face and communicated with even more by phone and more recently through e-mail. The financial burdens, fear of their unknown future, and worry about their family's security are paramount in these discussions as well as the feeling of being alone with no place to turn.

Words can barely convey the importance to my clients and the half a million others with younger-onset dementia of adding younger-onset Alzheimer's to the Social Security Compassionate Allowance Initiative list. By reducing the wait time for obtaining benefits from the two to four years that is now common to less than four to six months would be huge for

these families. It would relieve much of the worry about providing for their family, possibly losing their home, paying for their children's education, and meeting mounting medical bills. So many of these families are already scared to death and not knowing what is going to happen overwhelms them to the point that they cannot think clearly and make wise choices. They desperately need some one to reassure them, walk with them, and guide them in the weeks immediately after the diagnosis.

A major concern is loss of income and thus having to sell their home, liquidate savings and retirement funds, and the loss of opportunity for the spouse to recoup these losses after their death. If Alzheimer's Association staff and healthcare professionals could tell them from the beginning that with a diagnosis of younger-onset Alzheimer's disease the Social Security benefits are fast tracked and they will be determined to be eligible upon making application, it would change their outlook from hopeless to hopeful.

By restoring their hope, their worry is lessened and they could plan for their future more wisely knowing there will be funds to help meet immediate needs, for themselves and their family. One female care partner said her greatest fear was losing her home, something she and her husband had worked together to achieve since their marriage. A male care partner confided it would have prevented him from liquidating many of his prized possessions in order to have cash on hand to provide for his wife's care and medical costs.

I urge you on behalf of the young people yet to be diagnosed with this dread disease to proceed with implementing this Compassionate Allowances Initiative as soon as possible, thereby decreasing the wait time, frequent denials and appeals, which so frustrate and further incapacitate these people. Thank you.