

STATEMENT OF -----

-----, 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 ----- (age 61) and I am caregiver for my wife ----- (age 58). About 2004, ----- started having some perceptual issues. Based upon doctor's visits, we thought the problems were related to menopause. We spent time and effort in trying to deal with what we thought were the side effects of menopause. Finally, in 2007, ----- couldn't operate a calculator and had some mild trouble with eye-hand coordination. Her nurse practitioner at the time suggested that she get some psychological testing done. In November of 2007, ----- was diagnosed with younger-onset Alzheimer's.

Although she has many things she continues to be able to do, I grew increasingly uncomfortable with her being alone during the day when I was at work. Because she is very self-conscious about her condition, I wanted to move closer to our family for her happiness, and reduce the work time away required being by being a school administrator. I believe that I am the best person to care for -----, and wanted to do that. I was more fortunate than most, because I had a pension that I could retire on, and ----- started receiving social security disability benefits in May of the following year. The trouble with my retiring is that I won't be eligible for Medicare for five years. To maintain our family medical insurance would require

half of my pension, and we went through a lot of tension and worry about how I could quit my job, return closer to our family, and care for ----- . Tension and worry are not good for the patient or the caregiver and can accelerate the progress of the condition. Also, as you are

probably aware, being a caregiver usually reduces the life expectancy of those individuals as well. We spent time wondering, how can we get back to our family for support and get me time to be with ----- and maintain our family insurance? We definitely held off doing what was the best thing for ----- because of health insurance needs.

----- will be eligible for Medicare in May of 2010, and that will cut our insurance costs by about

60%. However, due to the nature of the disease, waiting until May of 2010 was too long to wait to make the moves we felt were needed. We are fortunate that we can borrow the \$10,000 needed against an insurance policy to get to May of 2010. I feel other families may not have this capability. Having ----- able to receive Medicare benefits earlier would have allowed us to move earlier and be in a more positive situation related the time window that we have. I believe a compassionate allowance initiative for younger-onset Alzheimer's would help families cope with the limited time and financial challenges when patients or caregivers have to quit work and deal with this disease. I hope you will give serious consideration to making this designation.