STATEMENT OF -----------, TEXAS for

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

JULY 29, 2009

I am a person with early-onset, early stage Alzheimer's disease. I was only 52 years old and couldn't have been more shocked when I went to the neurologist to get results from some testing that I had taken. I knew I was having some issues, but also thought there was nothing wrong, but when my employer considered firing me I said "wait and let me go to the doctor." When the neurologist opened the door she stood there in the door way and said "Ms. ------, you have Alzheimer's disease".

Approximately 9 months later I took a "medical leave" as it had become too destructive for me to continue my job. At that point I filed for Social Security Disability Benefits and this was a very long, frustrating and stressful process that I endured for the next 3 plus years.

I can only ask "Why?" Why does it take so long? Why do we have to make appeal after appeal? Those of us with Alzheimer's or dementia are never, ever going to any better, no way, no how, not even a 1% chance, so again I ask "why?" Why do we have to wait? Why put us through this frustrating, stressful and lengthy process when our minds are not clear to begin with and getting fuzzier every day?

I was very fortunate to have had a disability plan at work which paid me a percent of my salary; it wasn't as much as I had been making, but I was able to survive financially.

What about those who are not that fortunate and have no resources, no savings, no one to help with the bills, living paycheck to paycheck as many Americans do and then not being able to work? Do you realize that those with no resources become homeless, yes homeless. How are they supposed to keep calling Social Security for status, fill out paperwork, respond to many denied letters, filing appeal after appeal and have no mail box to receive correspondences? Why does someone whose mind is not clear have to live on the streets for 3 – 5 years until their benefits are approved, why?

Please, I beg of you to make changes so those of us whose minds are slowly slipping away do not have to go through this process and remember we are never, ever, no way, no how, not even a 1 percent chance of getting any better, never, ever.