

STATEMENT OF -----

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-----, **MINNESOTA**
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 individuals with Alzheimer's disease. I have the opportunity to see up close the profound impact families experience when someone far too young is diagnosed with Alzheimer's disease. First, they are devastated by the nature of the diagnosis—something they only thought would happen to an elderly person. Then, they must deal with the reality that while they will attempt to maintain their employment, all too soon it is taken away from them as the ability to function in the work setting quickly diminishes, and they may lose their job at the height of their career and earning power.

Losing employment is followed immediately by the loss of health coverage, often family coverage, and it is coupled with the difficulty of obtaining new coverage while carrying the diagnosis of this devastating illness. They have no medical insurance at the time when they need it the most, for themselves and for their family.

Families often share with me their frustration during the application process with the Social Security Administration. This frustration is often compounded by a deep, unconscious fear for their financial future. It is common for these families to have children who are college age, or even younger. The expenses of raising a family are at a peak that lasts for several years during which Alzheimer's disease is progressing and the family unit struggles every day to maintain balance and prepare for the future.

I have had the opportunity to take some of these families to Congressional offices to share their heartbreaking stories with our U. S. Senators and Representatives. Our delegation has been astounded to learn the heartbreak of younger onset and the difficulties families encounter with the Social Security Administration. The denial of SSDI coverage can become yet one more knot on a string of loss and sadness.

I am thrilled to have Younger-Onset Alzheimer's Disease considered for addition to the Compassionate Allowances initiative listing. While the number of families facing this situation is not significant in number, the impact on their lives is enormous.

On behalf of these individuals and their family members, please recognize this impact and add Younger-Onset Alzheimer's Disease to your list for Compassionate Allowance.