

STATEMENT OF -----

-----, **WISCONSIN**
for

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

JULY 29, 2009

If there is one thing I would like to convey, it is by the time a Younger-onset Alzheimer's disease and dementia patient is applying for Social Security disability they have been subjected to significant medical intervention, delays in diagnosis and bounced from one doctor to another.

If a person in their 70's goes to the doctor and complains about memory loss, not being able to complete basic tasks, behavior changes, etc., a doctor is going to look for Alzheimer's and Dementia. But when a patient in their 30's or 40's goes to see their doctor with the same set of symptoms for Alzheimer's – or in -----'s case Organic Brain Disease – it may be the last thing the doctor is going to look for.

Younger-onset Alzheimer's and dementia families deal with a different set of issues than their older counter parts. To simply get the diagnosis we had had to jump through "hoops" which dealt a devastating financial blow during the peak of our earning potential. Some of us have children who cannot grasp the changes in Mommy or Daddy and we are discriminated against because people don't understand that young people have dementia, too - our next door neighbor refers to ----- as "mental." The emotional toll it takes on our families is indescribable.

-----'s diagnosis of Organic Brain Disease stopped my dead in my tracks. His family went into denial and because of his odd behavior and friends, co-workers and family slowly faded into the woodwork. All our dreams of children and of traveling in our later years died in that instant.

By the time I applied for SSDI on -----'s behalf we had already spent significant money on health care – and I have excellent health benefits. I hired an attorney to help us with the appeal because it is understood that no one under 60 with a diagnosis of dementia gets SSDI the first time. No one. Financially, we have less money coming in because of the loss of -----'s salary, but we are spending more money to fight his disease.

As the caretaker, I was so overwhelmed by my “new life” that by the time I was applying for SSDI on -----'s behalf the idea of having to fight the federal government for benefits made me sick. I was angry and resentful about the money I'd spent for the attorney and thought about giving up. I am not sure how I made it though that summer ----- first lost his job and we applied for SSDI.

As I review my written testimony, I realize that my words cannot adequately describe what granting of the Compassionate Allowance would mean for people like ----- . I can only hope that as you look at the people in the room today, read our stories and listen to the testimony that somehow you understand and grant the Compassionate Allowance to people with early onset Alzheimer's, Organic Brain Disease and other dementias.

Thank you.