

**Statement of Harry Johns, President and CEO of the Alzheimer's Association
for the Social Security Administration's Compassionate Allowance Hearing
on Early-Onset Alzheimer's Disease and Related Dementias**

Commissioner Astrue and Distinguished Panel, I am Harry Johns, President and Chief Executive Officer of the Alzheimer's Association. I appreciate the opportunity to speak with you this morning. More importantly, Commissioner Astrue, the Alzheimer's Association appreciates your leadership in creating the Compassionate Allowances Initiative and your willingness to consider Alzheimer's disease and other dementias for inclusion in the list of Compassionate Allowance conditions. The Alzheimer's Association's incorporated name is the Alzheimer's Disease and Related Dementias Association, so we are grateful that you have already included Frontotemporal Dementia, Pick's Disease and Creutzfeldt Jakob Disease and hope that this hearing will result in similar decisions for Alzheimer's disease and other diseases that cause dementia in people under age 65. We believe the case is equally compelling for the latter conditions.

The Alzheimer's Association has been aware since its formation almost 30 years ago of younger individuals -- people in their 30's, 40's, 50's, and early 60s -- who have Alzheimer's disease and other diseases that cause dementia. In fact, when Alois Alzheimer identified this disease in 1906, he found it in a woman who was just a year younger than me. She was 51. Regrettably, for about 70 years, the problems we now so identify with Alzheimer's disease in our older population, weren't recognized as the same disease.

Once the science community recognized that the older population of people with Alzheimer's and other dementias was significantly larger, the pendulum swung too far in the other direction. For lack of data, our society did not recognize that those under age 65 with dementia, though a minority among dementia sufferers, was a significant population, a large cause in itself.

No conclusive information is available about how many people under age 65 have Alzheimer's disease or other dementias. However, we recently received data showing that approximately 200,000 people under age 65 with Alzheimer's and other dementias are currently in the Medicare system.

Over the past few years, as we have sought information about people under age 65 with Alzheimer's disease and other dementias, we have been shocked and saddened by the stories we've heard. People under age 65 with Alzheimer's and other dementias often lose their jobs-- they are fired or forced to retire--even before they are diagnosed. Some, who are aware of their increasing problems at work, seek a diagnosis and are fired when they tell their employer about the diagnosis. Others decide they must resign when they learn the diagnosis and recognize that they cannot fulfill their responsibilities to their employer, even though it likely means they will not be able to fulfill their responsibilities to their families. Many try to find another job that they will be able to manage. Some succeed in finding such work for a time, only to be fired or forced to retire again when it's clear that they cannot learn new skills and work routines.

In the past 3 years, the Alzheimer's Association has conducted Town Hall Meetings for people with early-stage Alzheimer's and other dementias. More than half of the people with early-stage Alzheimer's or dementia who participated in these meetings had been diagnosed before age 65. We have heard a lot from these people about the stigma of Alzheimer's and other dementias and the difficult experiences they have had with losing their jobs, income, and health insurance. More importantly for this hearing, we've heard a lot about problems many of them have had in applying for and being found eligible for Social Security Disability Income (SSDI). We have no data to determine how many younger people with Alzheimer's and other dementias have difficulty applying for and being found eligible for SSDI, and how many do not. But judging from what we hear in the Town Hall Meetings and from people who call our chapters across the country or our 24-hour nationwide telephone helpline, I believe that there are many, many people under age 65 with Alzheimer's and other dementias who have applied and been told they were ineligible; some have given up, and others have appealed, sometimes more than once, and eventually been found eligible. You will hear later today from one person who made it through the disability determination process easily and one couple that struggled for years.

You will also hear today about the science of Alzheimer's disease and other dementias and the impact of these conditions on the individual and on the family. Alzheimer's is truly a family disease by impact and even more so for those with early onset.

Just briefly, people with Alzheimer's disease and other dementias demonstrate observable symptoms in the early stages of their condition. Those with mild Alzheimer's or other dementias have clear deficits in recent memory and at least one other cognitive domain. They have an inability to complete even familiar tasks and functions, difficulty handling finances, and challenges with geographical orientation in their homes or businesses. Changes in personality occur frequently, including apathy, depression, and disinhibition.

The very diagnosis of Alzheimer's indicates significant enough cognitive impairment to interfere with daily living activities, including the ability to work. As their disease progresses, individuals with moderate Alzheimer's or other dementias are dependent on others for instrumental activities of daily living, such as using the telephone and shopping, and do not remember to take care of daily activities such as bathing and dressing. They may not recognize familiar people and can no longer safely operate motor vehicles, lawn mowers and other machines. Most are no longer able to operate common equipment such as computers or stoves. Irritability, paranoia, and disrupted sleep are common in moderate dementia.

Alzheimer's disease is a progressive, degenerative, and terminal illness. There is no treatment that stops or delays the progression of the disease. The few drugs currently approved only treat Alzheimer symptoms. For about half of the individuals who take them, these drugs offer a modest, temporary delay in the worsening of cognitive symptoms. However, they do not stop or even slow the progression of the disease from early memory loss through complete bodily dysfunction, on the way to ultimate death. There are no survivors of Alzheimer's disease.

While the Alzheimer's Association frequently hears from individuals under age 65 with Alzheimer's disease and other dementias that they are denied Social Security disability benefits upon initial application, they ultimately receive benefits at some level of the appeals process. It is because of the disease progression and lack of treatment to slow or prevent the course of the

disease, that individuals with Alzheimer's rarely, if ever, lose their appeals before an Administrative Law Judge. Yet, some individuals are forced to wait one, two or even three years to ultimately receive their benefits, which are then retroactive to their initial date of application. The emotional and financial costs to these individuals and their families are preventable. In addition, as you are well aware, long delays in the disability determination process are costly for the Social Security Administration. In the case of people with Alzheimer's disease and other dementias, these long delays are, and can be avoided.

Commissioner Astrue, you launched this Initiative in order to "accelerate the review of cases likely or certain to be approved." You stated that it is unacceptable for Americans to have to wait years to receive their benefits. We wholeheartedly agree. The Social Security Administration created this category of "compassionate allowance" to identify those conditions and diseases which, by definition, result in an individual's inability to work for at least 12 months. Given the terminal nature of Alzheimer's disease and other dementias, the disabilities that prohibit work in even the earliest stages of the disease, and the lack of disease-modifying treatments, it is clear that Alzheimer's disease and other dementias meet this criterion and should be included on the list of conditions for treatment under the Compassionate Allowance Initiative.

Thank you for the opportunity to talk with you about this very important topic.