

FOR IMMEDIATE RELEASE

Contact: Keri Pollock
Communications Director
Alzheimer's Association, Western & Central Washington State
12721 30th Ave NE, Suite 101, Seattle, WA 98125
800.848.7097 | keri.pollock@alz.org
www.alzwa.org

Alzheimer's at 56

[Seattle, WA, July 28, 2009] – Mention Alzheimer's and people generally envision someone in their 80s who can't remember names of family members, live on their own, or articulate clearly. This is how many perceive the 5.3 million Americans who have Alzheimer's.

What people don't recognize is the person in the early stages of the disease, living independently. What most people don't see – including many in the medical profession – are people like Dr. Hugh Larkin from Gig Harbor, WA, who was diagnosed in 2006 at age 56 with Young Onset Alzheimer's disease.

With a thriving medical practice and two sons in college, Dr. Larkin was forced to close his practice following his diagnosis. Happily married to his high school sweetheart, with what he considered to be the best years ahead of him, Hugh is just one of the estimated half million people in the United States who have been struck with Alzheimer's in their 50s, 40s, even 30s.

People with Young Onset face all the challenges of people with Alzheimer's ages 65+ and then some: when symptoms first appear, they are often misdiagnosed as conditions resulting from stress or depression because even medical professionals are distracted by the fact that, since age is the greatest risk factor, Alzheimer's "should" only strikes people over the age of 65.

For people under age 65 with Alzheimer's disease and related dementias, their diminished cognitive impairment can quickly reach a point where they can no longer maintain gainful employment. Currently, many people with younger-onset Alzheimer's disease and related dementias face multiple challenges when applying for SSDI, including a lengthy decision process and multiple appeals. They are falling through the cracks of the healthcare system and often depleting their family's savings leaving spouses and children challenged when it comes time to plan for their future.

On Wednesday, July 29, the Social Security Administration (SSA) is holding a hearing examining whether people with younger-onset Alzheimer's disease and related dementias (under age 65) should be included in SSA's Compassionate Allowances Initiative for Social Security benefits.

The Compassionate Allowances Initiative is an effort to improve and expedite the Social Security disability (SSDI) determination process for a recognized class of medical conditions and diseases that are severely debilitating and/or life threatening that prevent individuals from being able to work for at least 12 months.

The hearing will feature testimony from five panels, including experts in the field as well as those directly affected by Alzheimer's and related dementias. Association panelists include Harry Johns, president and CEO; Jay Jones, young-stage advisor, Southeast Florida Chapter; Laura Jones, Southeast Florida Chapter; and Joyce Simons, young-stage advisor, New York City Chapter.

SSA is broadcasting a live webcast on July 29 from 9 a.m.–4:30 pm Central at www.ssa.gov.

If SSA decides to include younger-onset Alzheimer's disease and related dementias on the list of Compassionate Allowances, it would simplify and streamline the SSDI application process, decrease the wait time for benefits and help people access the assistance they need. The hearing will provide SSA with an opportunity to be briefed and introduced to the broad range of issues concerning those with younger-onset Alzheimer's and other dementias.

Hearing Agenda <http://www.ssa.gov/compassionateallowances/hearings0729.htm>

The panelists providing testimony were chosen by the Social Security Administration.

9–11:45 a.m.

Panel Presentations

Panel 1: Opening statements by Social Security commissioner, deputy commissioners and NIH deputy directors.

Panel 2: Overview of Younger-Onset Alzheimer's Disease

Panel 3: Younger-Onset Alzheimer's Disease: Today and Tomorrow

Noon–1:30 p.m.

Lunch Break

1:30–4 p.m.

Panel Presentations

Panel 4: Overview of Related Dementias

Panel 5: Individuals, Caregivers and Advocates

4-4:30 p.m.

SSA Closing Remarks

An official Alzheimer's Association statement will be posted on July 29. The hearing recording and written testimony will be available on July 30.