

## THE BRAINS BEHIND SAVING YOURS:

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## Alzheimer's Association Advocate Shares Personal Experience with Alzheimer's Disease, Urges Congress to Increase Support for Caregivers

Caregiver Encourages Passage of the HOPE for Alzheimer's Act on the Heels of CMS Proposal to Improve Access to Care Planning Services

**WASHINGTON, D.C., July 13, 2016** – Speaking on behalf of the more than 15 million Americans providing care to the more than 5 million Americans living with Alzheimer's disease today, Alzheimer's Association advocate Connie Bastek-Karasow urged Congress to work to improve the Medicare system to provide better care for American families facing this diagnosis until a scientific breakthrough leads to an effective treatment or cure for Alzheimer's disease.

A caregiver for her husband Mark, Bastek-Karasow's remarks came in testimony before the U.S. Senate Finance Committee Subcommittee on Health Care hearing entitled "Alzheimer's Disease: The Struggle for Families, a Looming Crisis for Medicare." During the hearing Bastek-Karasow shared the story of her husband's long path - including multiple doctors, grueling testing, contradictory diagnoses, and a clinical trial - to a confirmed diagnosis of Alzheimer's disease. She also noted the importance of passing legislation like the HOPE for Alzheimer's Act which would allow individuals diagnosed with Alzheimer's disease to have a care planning session with a health care provider.

"If HOPE had been in place at the time of Mark's diagnosis, I am certain that we would have felt much less alone in this fight," said Bastek-Karasow. Her testimony came just days after the Centers for Medicare & Medicaid Services announced a new service based on HOPE which would allow those diagnosed with Alzheimer's disease to receive comprehensive care planning services through a medical visit.

"Alzheimer's is a devastating disease that exacts a tremendous personal and economic toll on individuals, families, and our health care system," said Robert Egge, Alzheimer's Association Chief Public Policy Officer. "In addition to increased research funding to ultimately find a way to effectively slow, prevent, or cure Alzheimer's we need an equally strong investment in caring for those living with the disease today and their families."

Bastek-Karasow also spoke to the Subcommittee about her husband's participation in the Imaging Dementia - Evidence for Amyloid Scanning (IDEAS) clinical trial. Backed by the Alzheimer's Association and with funding by Medicare, the IDEAS Study will determine the clinical usefulness on patient-oriented outcomes of a brain PET scan that detects amyloid plaques, a hallmark of Alzheimer's disease.

"This study is particularly helpful in determining a diagnosis for people like Mark who do not present with typical dementia or cognitive decline," said Bastek-Karasow. "When Mark had the PET scan that confirmed his diagnosis, all of the debate, searching, and uncertainty was put to rest and the real work of living with the disease began."

Today, more than five million people are living with Alzheimer's, the most expensive disease in the nation and the only leading cause of death in the U.S. without a way to prevent, cure or even slow its progression. Total national cost of caring for those with Alzheimer's and other dementias is estimated at \$236 billion (excluding unpaid caregiving), of which \$160 billion is the cost to Medicare and Medicaid.

For more information on Alzheimer's disease, visit alz.org.

## Alzheimer's Association®

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer's. For more information, visit alz.org.