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## MY NEW YEAR'S "WISH LIST" FOR A NATIONAL ALZHEIMER'S AGENDA

January 10, 2014 - Allan S. Vann

As a caregiver for my wife, diagnosed with Alzheimer's Disease (AD) in 2009 at the age of 63, here's my brief "wish list" for a national Alzheimer's agenda.

### **Funding changes:**

First and foremost, our leaders in Congress must make Alzheimer's a priority in the FY2014 budget by increasing funding for treatment and NIH research. Beyond that, the government must also provide funding for states to disburse to local research labs working on neurodegenerative diseases. Funding should also subsidize clinical trials for potentially new AD medications, but medication labels must note that medication was proven effective only for the number of weeks that the trial lasted.

States should also provide grants to local AD organizations (such as the Long Island Alzheimer's Foundation, where I live) that help those with AD and their caregivers. Assisted living facilities, non-profit social organizations, hospitals, and nursing homes should also receive grants. Money can be used to create more caregiver support groups, day care and respite programs, provide companion services and home health aides, and support ongoing training programs for AD healthcare personnel

### **Changes in doctor/patient/caregiver protocols:**

Doctors must pay more attention to what caregivers tell them about their loved ones during office visits! We already have research supporting the effectiveness of screening for AD symptoms through the AD8, a 2-minute questionnaire given to caregivers. Such tests should be routinely administered to any caregivers who express concerns about a loved one ... regardless of whether that loved one is symptomatic of dementia or not when in the doctor's presence.

Upon issuing an AD diagnosis, doctors should be required to inform patients and their caregivers about caregiver support groups and should provide a brief handout explaining the stages of the degenerative progression of AD over time. Too many caregivers are unaware of support groups and how they can be helpful. Similarly, too many caregivers are not aware of how quickly one with AD can decline and how important it is to make end-of-life decisions sooner rather than later.

Doctors should also be required to report every AD diagnosis to their state Department of Motor Vehicles, with surrender of driver's licenses mandated no later than one year after diagnosis. By definition, an AD diagnosis implies mental impairment that will, eventually, impact one's ability to drive a vehicle safely. A person with AD who continues to drive long after diagnosis potentially places that person, anyone else inside that person's vehicle, and bystanders in harm's way unnecessarily.

### **Hearing caregiver voices:**

Local, state, and national AD advisory panels should be required to seek more input directly from 24/7 caregivers. Unless someone lives 24/7 with a loved one who has AD, one cannot possibly have the remotest idea of what an AD caregiver's life is like. **The National Alzheimer's Project Act (NAPA)**, for example, only has one 24/7 caregiver on its Advisory Panel. Without hearing more caregiver voices, NAPA is not as inclusive as it should be.

### **The need for action ... now:**

It is now more than 3 years since NAPA was created, yet NIH continues to fund AD research near the same relatively low levels as before. Neither NAPA recommendations nor proposed Senate and House bills for increased funding have resulted in substantially increased federal funding. We must have the political will as a nation to make tough choices in difficult economic times. The time for our country to deal with the human and economic burdens of Alzheimer's is now.