ALZHEIMER'S ASSOCIATION **Update**

Highlights of Alzheimer's Association news and events of interest to the medical and scientific community.

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State surveys show 1 in 9 residents age 45 and older have subjective cognitive decline

Collecting population-based data on subjective cognitive decline (SCD) has been a priority for the Alzheimer's Association for several years, as emerging research suggests that SCD is one of the earliest warning signs of Alzheimer's disease.

Thanks to state Alzheimer's Association public policy officers who worked directly with their state public health departments—with technical assistance from the Association's Public Policy Division and funding from the Centers for Disease Control and Prevention (CDC)—questions about cognitive function were added to states' annual Behavioral Risk Factor Surveillance System (BRFSS) public health surveys. From 2011 to 2013, the Association obtained agreements from 45 states, the District of Columbia (DC), and Puerto Rico to collect data on SCD.

Earlier this year, the CDC released data from the 19 states and Puerto Rico that asked the questions in 2013. The data showed that 11 percent of people age 45 and older had SCD—that is, they reported increased confusion or memory loss in the previous 12 months. Among people with SCD, only 24 percent said they had discussed the matter with a health care provider. In addition, 80 percent had at least one other chronic condition, and 44 percent said their memory problems caused functional difficulties, such as with the ability to work or perform household chores.

Some populations bear a disproportionate impact. The 2013 results show that African-Americans were 31 percent more likely than whites and 40 percent more likely than Hispanics to report SCD. Individuals with lower levels of education also were more likely to have SCD. For example, 15.7 percent of people who did not graduate from high school had SCD compared with 7.8 percent of college graduates. The 2013 data—as well as data from 2011 and 2012—are available at alz.org/publichealth/data-collection.asp.

While the research community is increasingly examining SCD from a clinical perspective, SCD data on a population level are essential to help public health officials and policymakers identify trends, develop effective policy, and plan for the possible future burden of Alzheimer's disease in their states. That is why, since 2008, the collection of BRFSS data about SCD has been a priority of the Alzheimer's Association and the Healthy Brain Initiative (HBI). The HBI brings together the Alzheimer's Association, CDC, and other partners to stimulate awareness of and action on Alzheimer's disease as a public health issue. The central guiding document of the HBI is *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013–2018*, which includes specific action items that state public health officials can take to promote cognitive functioning, address cognitive impairment, and help meet the needs of caregivers. SCD data collection is one of those action items.

To begin looking at trends—as well as to obtain a complete snapshot of SCD in the United States—the Alzheimer's Association, in partnership with CDC, set a policy goal of having all 50 states, DC, and Puerto Rico ask a series of questions not only about SCD but also about caregiving in 2015 or 2016. To date, 49 states, DC, and Puerto Rico asked or are asking the cognitive questions in 2015 or 2016, and 38 states (plus DC and Puerto Rico) asked or are asking the caregiving questions. In fall 2016, the CDC will release the 2015 BRFSS cognitive and caregiver data in what will become the nation's largest set of population-based data on SCD and caregiving for people with dementia.

For more information about BRFSS, the HBI, and the *Road Map*, visit alz.org/publichealth or cdc.gov/aging.

Registration for amyloid PET study open to dementia specialists and imaging centers

Dementia specialists and positron-emission tomography (PET) imaging providers can now register to participate in the Imaging Dementia–Evidence for Amyloid Scanning (IDEAS) Study at IDEAS-Study.org.

Results from the IDEAS Study will be used to determine the clinical usefulness and value of brain PET scanning for the Alzheimer's disease protein beta-amyloid in diagnosing and managing treatment of people with mild cognitive impairment (MCI) or dementia where the cause is uncertain.

The IDEAS Study is led by the Alzheimer's Association and managed by the American College of Radiology and American College of Radiology Imaging Network. The Centers for Medicare & Medicaid Services (CMS) will provide reimbursement to participating PET facilities for the costs associated with the PET scans. The Alzheimer's Association and a consortium of PET radiotracer manufacturers are providing additional funding.

The study will follow almost 19,000 Medicare beneficiaries for up to 4 years to provide sufficient evidence that knowing the results of an amyloid PET scan may help physicians make more informed treatment decisions. The total budget for the study is estimated at $100 million.

"There is tremendous interest in this groundbreaking trial," said Gil Rabinovici, MD, IDEAS Study chair and associate professor of neurology at the University of California, San Francisco. "Amyloid PET can be incredibly useful in assessing diagnostically challenging patients with MCI or dementia. However, patient access has been severely restricted by lack of reimbursement. Dementia specialists who participate in the study will be able to offer easier access to appropriate patients and use amyloid status to refine their diagnosis and optimize the management of these individuals. Participating providers also will help to amass sufficient data to assess whether amyloid imaging has a positive impact on patient outcomes that could lead to expansion of Medicare coverage for this important diagnostic tool."

Diagnosing Alzheimer's is complex, and no single test can detect the disease. Diagnosis is currently based on a person's history, physical examination, and cognitive testing. When a comprehensive exam does not lead to a clear diagnosis of the cause of cognitive impairment, it can be frustrating for patients, families, and physicians and may have a negative impact on patient care. For example, some people improperly diagnosed may be prescribed the wrong medications or no medications at all when they may be beneficial.

"The Alzheimer's Association is leading the IDEAS Study because we understand the importance of early and accurate diagnosis and management of dementia for individuals with the disease and their families," said Maria Carrillo, PhD, Alzheimer's Association chief science officer and IDEAS Study co-chair. "There has never been a study of this scale to evaluate the clinical value of brain amyloid imaging in diagnosing and caring for those affected by Alzheimer's."

As participating providers in the IDEAS Study, dementia specialists will team with radiologists and nuclear medicine physicians at qualified PET facilities. Dementia specialists will enroll patients whose cases meet the study enrollment criteria and refer them for an amyloid PET scan. Amyloid PET scans will be performed and interpreted by a nuclear medicine physician or radiologist, with results being provided to the ordering physician for disclosure to the patient and to support further diagnostic decisions.

Board-certified neurologists, psychiatrists, and geriatric medicine physicians interested in becoming referring physicians for the IDEAS Study, and PET facilities that would like to join the study as imaging sites, may apply for participation at IDEAS-Study.org using the login/register portal. Background on the study, requirements for participation, and frequently asked questions are available on the website.

Record-breaking number of Alzheimer's advocates converge in DC for Advocacy Forum

A record number of Alzheimer's advocates—nearly 1200—met in Washington, D.C., April 4–6 for the 2016 Alzheimer's Association Advocacy Forum. They met with state representatives on Capitol Hill to encourage congressional action on three key items: to increase the commitment to Alzheimer's research by increasing funding for Alzheimer's research by at least an additional $400 million in fiscal year 2017; to improve access to care planning by cosponsoring the Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act (S. 857/H.R. 1559); and to educate providers on palliative and hospice care by cosponsoring the Palliative Care and Hospice Education and Training Act (S. 2748/H.R. 3119).

The event included a Roll Call of states' policy accomplishments in the last year, advocacy training, and a dinner honoring public leaders working to advance the Alzheimer's cause. On the final day, advocates were invited to attend the U.S. Senate Special Committee on Aging hearing, "Finding a Cure: Assessing Progress Toward the Goal of Ending Alzheimer's by 2025."

In his welcome letter, Advocacy Forum Chair Bob Marino, a member at large of the Alzheimer's Impact Movement Board and recipient of the Association's Maureen Reagan Outstanding Advocate Award, told advocates, "You represent the very best of who we are through your collective voice, passion and commitment to speak out on behalf of friends, family and neighbors affected by the devastation of Alzheimer's disease…. Because of you … we've witnessed some remarkable milestones together, from passage of the National Family Caregiver Support Program and expedited access to Social Security Disability Insurance for younger-onset individuals to the National Alzheimer's Project Act (NAPA) and launch of the inaugural national Alzheimer's plan in 2012.

"[Y]our advocacy [has] achieved hard-fought, additional National Institutes of Health research funding in multiple years, culminating with the inclusion of the Alzheimer's Accountability Act in 2014's Omnibus Appropriations Bill and the FY2016 budget's unprecedented $350 million increase for Alzheimer's research, bringing the total to $936 million. This is double the amount from when we all worked with Congress to unanimously pass NAPA five years ago."

Impact on Capitol Hill

At the opening general session, advocates heard from congressional Alzheimer's supporters, including Sen. Shelley Moore Capito (R-W.Va.). Capito, who lost both parents to Alzheimer's disease, is a lead sponsor of the HOPE for Alzheimer's Act, which would increase access to information on care and support for newly diagnosed individuals and their families, and ensure that an Alzheimer's or dementia diagnosis is documented in the individual's medical record. Her personal experience informed remarks that focused on the importance of assisting caregivers. "I don't have to go far to tell you why I'm interested in this cause," Capito said. "This is still very fresh… We have to do more not only to find a cure but to help families dealing with Alzheimer's."