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March 26, 2012

Helen Lamont, PhD
HHS Office of the Assistant Secretary for Planning and Evaluation
Room 242E, Humphrey Building
200 Independence Avenue, SW
Washington DC, 20201

RE: AAN Comments on Draft *National Plan to Address Alzheimer's Disease*

Dear Dr. Lamont,

On behalf of the American Academy of Neurology, I would like to commend the Department of Health and Human Services and its federal partners, the Interagency Group on Alzheimer's Disease and Related Dementias, and the Advisory Council on Alzheimer's Research, Care, and Services for your efforts to develop the highly comprehensive and needed *National Plan to Address Alzheimer's Disease (Plan)*.

The American Academy of Neurology (AAN) is the largest scientific and professional organization for neurology in the United States. Representing more than 25,000 neurologists and neuroscience professionals, the AAN strives to promote the highest quality patient centered neurologic care. The AAN is proud to support the overall Plan and fully supports the vision of a nation free of Alzheimer's disease. The AAN is further pleased that a neurologist, Dr. Ron Petersen, was named as chairman of the Advisory Council.

The AAN is committed to playing an active role in supporting the objectives of the Plan. Our feedback in the following areas is provided for your consideration as you refine the Plan framework:

- Neurologists' Role in Alzheimer's Diagnosis and Treatment
- Strategy 1.A: Identify Research Priorities and Milestones
- Strategy 2.A: Build a Workforce with the Skills to Provide High-Quality Care
- Quality Measurement Considerations
- Current AAN Dementia-related Resources
- Submission to the CMI on Alzheimer's Care Delivery
- Concluding Remarks

Neurologists' Role in Alzheimer's Diagnosis and Treatment

The science and practice of neurology are integral to efforts to prevent Alzheimer's disease (AD), diagnose it, treat it, and slow its progression, as well as, provide support for patients suffering from the disease and their caregivers. Neurologists are specifically trained to manage AD and other chronic disorders of the brain and central nervous system.

Neurologists:

- Conduct basic and translational AD research
- Provide a comprehensive assessment including clinical diagnostic evaluation and evaluation of cognitive deterioration over time
- Make decisions regarding treatment for patients with AD

- Engage in follow-up visits every three to six months for patients with AD
- Provide patients and caregivers with decision aids, such as comprehensive end-of-life counseling and advance care planning

Independently, and as a part of multidisciplinary teams, neurologists have been at the forefront of research and treatment of AD. The role of the neurologist in the care continuum of AD is critical.

Many factors contribute to the current variations in care that patients with AD receive in the US. The AAN believes that improving care coordination among health care providers, strengthening education and support for AD caregivers, and increasing rates of early diagnosis would have a significant impact.

Strategy 1.A.: Identify Research Priorities and Milestones

The AAN strongly supports increased investment in AD research. Current funding levels are vastly disproportionate to impact of the disease now, and will be greatly exacerbated as prevalence increases in the future as the US population ages if funding trends remain unaltered. In addition, there is a tremendous gap between the research budgets for AD and dementia (approximately \$450 million) and the research budgets for other diseases like HIV/AIDs (approximately \$3 billion). The AAN believes in the need to raise the profile of AD research to bring it in line with its present and expected impact to the country.

Strategy 2.A: Build a Workforce with the Skills to Provide High-Quality Care

Expanded educational efforts are important in reducing care variations and preparing the health care workforce for an aging population. However, the AAN would note further support for expanding the supply of well-trained specialists is critical as more complex diagnostic tests and AD therapies become available.

The AAN agrees that a sufficient workforce is necessary to have high quality health care. Though reimbursement issues are not directly addressed in the Plan, they undoubtedly shape care delivery. Spending needed time face-to-face with patients diagnosing and coordinating care for complex neurologic diseases such as AD is undervalued in the current fee-for-service payment model. A lack of proper payment threatens the future supply of individuals trained specifically in neurology, which is of particular concern since neurologists are key to a timely diagnosis.

There is a large role for case managers to handle some of the social aspects of AD care, including the provision of support or information about next steps to caregivers, so that physician can focus on medical issues.

Quality Measurement Considerations

Since there is still limited evidence and effective treatments for AD, it is intrinsically difficult to develop high standard quality measures. However, the AAN agrees that care quality should be measured to the extent possible, and has developed a quality measure set for dementia that was recently approved by the American Medical Association (AMA) Physician Consortium for Performance Improvement (PCPI).

Current AAN Dementia-related Resources

AAN evidence-based guideline documents related to dementia:

- Update: Evaluation and Management of Driving Risk in Dementia
- Detection of Dementia and Mild Cognitive Impairment (currently under update)
- Diagnosis of Dementia (currently under update)
- Management of Dementia

View the guideline documents here:

<http://www.aan.com/practice/guideline/index.cfm?fuseaction=home.welcome&Topics=15&keywords=&Submit=Search+Guidelines>

AAN quality measures related to dementia:

- Caregiver Education and Support
- Cognitive Assessment
- Counseling Regarding Risks of Driving
- Counseling Regarding Safety Concerns
- Functional Status Assessment
- Management of Neuropsychiatric Symptoms
- Neuropsychiatric Symptom Assessment
- Palliative Care Counseling and Advance Care Planning
- Screening for Depressive Symptoms
- Staging of Dementia

View the quality measures here (must download after clicking on the link):

<http://www.ama-assn.org/apps/listserv/x-check/qmeasure.cgi?submit=PCPI>

Submission to the CMI on Alzheimer's Care Delivery

The AAN met with the Center for Medicare and Medicaid Innovation in early 2012 to discuss a suggested concept for modernizing the way care is delivered to patients with AD through a cooperative care team including neurologists, geriatricians/primary care physicians, geriatric psychologists, neuropsychologists, case managers, social workers, nurses, dietitians, and pharmacists. The concept goes on to address a major problem in the current delivery system for AD care: the misalignment of financial incentives that are causing monetary constraints to providing coordinated care.

View AAN's suggested concept here: <http://www.aan.com/globals/axon/assets/9408.pdf>

Concluding Remarks

Broad collaborations with private and non-profit entities should be encouraged and incentivized at the grassroots level to accomplish many of the goals outlined in the Plan, especially those involving caregiver support and quality of life interventions for patients. The AAN stands ready to assist by recommending content experts (including researchers, clinicians, educators, and specialists), publicizing the Advisory Council's efforts, and reviewing and dissemination of its work. The AAN remains committed to partnering with other organizations to prevent and reduce the burdens of this devastating disease. We appreciate your consideration of our comments. Please direct any questions, requests for clarification, or dialogue regarding our comments to Katie Shepard at (651) 695-2783 or kshepard@aan.com.

Sincerely,



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President, American Academy of Neurology

Cc: Catherine M. Rydell, CAE
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