AFTD
The Association for
Frontotemporal Degeneration
Opening the gateway to help and a cure

Radnor Station Building 2 • Suite 320
290 King of Prussia Road
Radnor, PA 19087
Tel 267-514-7221
Toll-free 866-507-7222
www.theaftd.org

Helen Lamont, Ph.D
HHS Office of the Assistant Secretary for Planning and Evaluation
Room 424E, Humphrey Building
200 Independence Avenue, SW
Washington DC, 20201 February 8, 2012

Re: The Association for Frontotemporal Degeneration (AFTD) comments on the Draft Framework for the National Plan to Address Alzheimer's Disease

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Dear Dr. Lamont,

The Association for Frontotemporal Degeneration (AFTD) congratulates the Advisory Council of the National Alzheimer's Project on the creation of the draft National Plan to Address Alzheimer's Disease (AD) (the draft plan). The draft plan is a major step forward in meeting the current and future challenges posed by progressive neurological diseases for the benefit of all who are affected by these devastating illnesses.

AFTD is honored to offer our input on behalf of the thousands of Americans living and working with frontotemporal degeneration (FTD), a group of clinical disorders resulting from a progressive loss of neurons in the frontal and/or temporal lobes of the brain. AD and FTD are related by pathological inclusions, often called neurofibrillary tangles, of the essential brain protein tau but differ in many critical ways. Memory loss, the characteristic symptom of AD, is rare in FTD and, when it does occur, is most often seen only during the later stages of FTD. The initial presentation of FTD can comprise a mix of symptoms, including: changes in behavior and personality diminished cognitive and executive functioning, language and communication problems, as well as motor impairments similar to those found in ALS or Parkinson's disease. FTD progresses unpredictably but inevitably results in complete dependence on medical care to sustain life during the final stages of the disease.

The average age of disease onset in FTD is in the late 50's, about a decade earlier than in AD. This difference poses special challenges shared only by the small percentage of people with the early-onset form of AD. Accessing insurance and finding appropriate health care for a debilitating neurological disease is a tremendous challenge for people under the age of retirement. Furthermore, the stigma associated with cognitive symptoms like dementia for people in their 40's-60's combined with a lack of public and professional awareness of FTD can create an overwhelming sense of isolation for people and families coping with FTD.

As an organization whose mission is devoted exclusively to this "related dementia", we believe that the inclusion of language in the draft plan explicitly addressing the distinct challenges posed by FTD and the related dementias will enable the proposed Actions and Strategies to better meet the needs of those affected by a non-Alzheimer's neurological disease. We strongly urge HHS to solicit input from experts and members of non-Alzheimer's disease communities and to specifically include such individuals as members of the task force detailed by Action 2.H.1 under Strategy 2.H.

Goal 1: Prevention and Treatment by 2025.

AD and FTD are related through a shared underlying pathology. This connection offers exciting research prospects with enormous potential for AD and FTD patients alike. Therapeutic compounds that target the protein tau could have equally effective application for treating both diseases. FTD offers pharmaceutical companies opportunities for drug development not available with AD, such as a larger number of cases related to identified mutations on a small number of genes and a regulatory status to facilitate progress toward clinical drug trials. It is our sincere hope that the draft plan will stimulate aggressive efforts to exploit this point of mutual interest for the sake of both FTD and AD patients and their families.

Goal 2: Care Quality and Efficiency

The primary obstacle to the efficient delivery of high-quality care for FTD in any professional setting is the overwhelming lack of qualified providers experienced in the diagnosis and treatment of FTD. Obtaining a diagnosis of FTD often takes several years, an amount of time equal to ¼ or more of the total life expectancy for some patients, and like AD a definitive diagnosis is still only obtainable by autopsy. Ambiguity in diagnosis during the life of the patient complicates care, clinical trial recruitment, financial planning and all other aspects of coping with a neurodegenerative disease of any kind. Reliable diagnoses that accurately differentiate AD from FTD and all other related diseases would benefit everyone. Once diagnosed, the only professional care available to those with FTD is by providers who advertise services with phrases like "Memory Care" or "Dementia Services" that are intended for people with AD. Some who have FTD, especially people in their 50's or 60's, fail to realize that such resources even apply to them since they do not have memory problems and dementia is widely perceived as a condition that affects only senior citizens. In order to measure and improve care for people affected by FTD any quality improvement tool developed through the draft plan must include data, information, and content addressing the scarcity of professional expertise and knowledge of FTD and recognize the enormous challenge patients and families face in accessing appropriate healthcare services that is not experienced by most of those with AD.

Goal 3: Expanded Support for Patients and Caregivers

Due to the earlier average age of disease onset relative to AD, FTD is more likely to strike people who are still employed and raising a family and inevitably deprives them of their ability to function in either a professional or private capacity. FTD robs families of a parent, and makes experienced professionals incapable of successfully concluding a career. The paucity of public awareness and scarcity of professional expertise can combine with the debilitating symptoms of FTD and throw entire families into personal, financial, and legal turmoil prior to diagnosis. Thus magnifying the impact of FTD on not only the healthcare system, but all other social and legal systems well beyond what is expected of a rare disease. Currently the main source of support for FTD patients and caregivers is extended families, close friends, and perhaps most importantly, other FTD caregivers. The need for strategies and action to expand support for patients and caregivers around the unique challenges posed by FTD is desperate.

Goal 4: Public awareness and Engagement

AFTD respectfully submits that without language explicitly describing the differences between the etiology, demographics and symptoms of FTD and AD, and the distinct challenges these differences impose on patients, caregivers, and the health care system as a whole, the draft plan will not successfully attain this goal for stakeholders involved with FTD. When FTD is subsumed under the phrase "related disorders" critical distinctions are lost, promoting the mistaken belief that dementia is a disease synonymous with AD rather than a symptom with a variety of causes. This, in turn, leads many healthcare professionals across all settings to treat people as if they have AD regardless of their actual diagnosis and provide them with inappropriate care which may even cause harm. Furthermore, when families and patients fail to respond as expected to the inappropriate care they receive they are too often denied care entirely rather than offered alternatives, exacerbating the sense of helplessness and the stigma that is all too common in those diagnosed with FTD. Unless more explicit attention is given to how FTD, and other neurological diseases differ from AD any increase in public awareness and engagement achieved through the draft plan will fail to fully benefit patients, families and caregivers coping with FTD and other neurological disease beside AD.

Goal 5: Improved data infrastructure.

Any data infrastructure created as part of the draft plan needs to be designed to include fields, criteria, and values specific to the impact of FTD, and other non-Alzheimer's diseases, on patients, families, and healthcare systems, if it is to benefit those with a neurological disease besides AD.

Respectfully submitted,

Susan L-J Dickinson, MS, CGC
Executive Director
The Association for Frontotemporal Degeneration
Radnor Station Building 2, Suite 320
290 King of Prussia Road
Radnor, PA 19087

Marsel Mesulam

M Marsel Mesulam, MD
Chair, AFTD Medical Advisory Council
Professor of Neurology
Director, **Cognitive Neurology and Alzheimer's Disease Center**
Northwestern University
Feinberg School of Medicine
Searle Building Room 11-453
320 E Superior
Chicago IL 60611