Alzheimer's experts provide strategic roadmap to tackle the disease

September 7 2012

This week, a strategic roadmap to help to the nation's health care system cope with the impending public health crisis caused Alzheimer's disease and related dementia will be published in *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*. The plan aims to link the latest scientific findings with clinical care and bring together patients, families, scientists, pharmaceutical companies, regulatory agencies, and advocacy organizations behind a common set of prioritized goals. The consensus document is the outcome of a June meeting of leading Alzheimer's researchers, advocates and clinicians, who gathered as part of the Marian S. Ware Alzheimer Program at the University of Pennsylvania.

Today, 5.4 million people are living with the disease, and more than 15 million Americans are caring for persons with Alzheimer's and other dementias, according to the Alzheimer's Association. Alzheimer's disease is the sixth-leading cause of death in the United States and the only cause of death among the top 10 in the United States that cannot be prevented, cured, or even slowed.

"Our plan aims to provide good quality care for affected patients and families, advance our understanding of the pathophysiology and natural history of AD and other dementias, develop effective treatments to slow or prevent these diseases, and translate scientific advances successfully into policy and practice," the authors wrote.

The experts developed a prioritized and integrated set of recommendations after meeting in June at Penn. Four workgroups,

focusing on Biomarkers, Clinical Care and Health Services Research, Drug Development and Health Economics, Policy and Ethics, had met separately leading up to the June conference. The document details recommendations from each group, and prioritizes the key recommendations from the paper, including:

- Speed the translation of research discoveries into clinical practice by revising the regulatory process and incentivize the pharmaceutical industry to develop AD drugs.
- Establish a diverse registry of older adults with and without dementia.
- Develop a risk stratification model that incorporates demographic, genetic, biologic, cognitive and environmental markers.
- Increase support to advance valuable care for patients affected with AD and their caregivers.
- Consider legislation requiring that, until the clinical value of biomarkers is fully understood, information gained through biomarker studies cannot be considered in insurance or employment decisions.

"This plan addresses the needs of a truly responsive health-care system: to integrate healthcare and social services as well as research and educational programs that support people with Alzheimer's, family members, and other caregivers along an individualized and changing illness trajectory ," said lead author Mary Naylor, PhD, RN. Dr. Naylor is the Marian S. Ware Professor in Gerontology; Director of NewCourtland Center for Transitions and Health at the University of Pennsylvania School of Nursing.

An accompanying editorial in the journal notes that the Ware Invitational Summit document may serve as an important tool for the

upcoming U.S. National Plan to Address Alzheimer's Disease, as it provides concrete, achievable policy ideas, being mindful of budget constraints and cost-effectiveness.

"Alzheimer's is an enormous and complex disease, and we believe that creative thinking, repurposing of existing funds, vigilance in reducing waste, and a constant focus on cost effectiveness will help make these recommendations a much-needed reality," said John Trojanowski, MD, PhD, senior author, director of the National Institute of Aging-funded Penn Alzheimer's Disease Core Center and is professor of Pathology and Laboratory Medicine in the Perelman School of Medicine at the University of Pennsylvania.

"The diverse perspectives collected in this report provide constructive, ethical, cost-effective guidance for policymakers," said second author Jason Karlawish, MD, associate director of the Penn Memory Center and professor of Medicine and Medical Ethics and Health Policy in the Perelman School of Medicine. "The recommendations serve as a clear roadmap to bring caregivers, researchers, clinicians, and advocacy groups together and provide them much-needed support now and in the future."

The Ware Invitational Summit brought together experts from academia; industry; government agencies and advocacy and nonprofit groups – including the meeting's co-convener, The Campaign to Prevent Alzheimer's Disease by 2020. The conference and editorial assistance were supported by the Marian S. Ware 2006 CWG Charitable Lead Annuity Trust and held at the University of Pennsylvania on June 20-21, 2012.

If pieces of the plan are implemented globally - by government, private organizations and medical institutions alike - the authors' aspirations are that treatments can be developed within the next decade to improve or

prevent AD; earlier diagnosis will give better options to patients ; and high-quality, effective care will be available to people with <u>dementia</u> throughout the course of their disease.

Provided by University of Pennsylvania School of Medicine