DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

Taking a Toll on Families and the Economy: The Rising Cost of Alzheimer's in America

Witness appearing before the

Senate Subcommittee on Labor – HHS – Education Appropriations

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analysis[2] suggest that 35.6 million people lived with dementia worldwide in 2010, with numbers expected to double almost every 20 years, to 65.7 million in 2030 and 115.4 million in 2050.

This disease is not just a burden on our health; it is also a burden on our economy. Recently, NIH-supported economists calculated that the costs in 2010 to the U.S. health care and long-term care systems for caring for people with Alzheimer's disease were between $159 billion and $215 billion, depending on how caregiver costs were assessed. The researchers estimated direct costs of dementia care purchased in the market in 2010 at $109 billion. To place that figure in context, that same year, direct health costs for heart disease and cancer were estimated at $102 billion and $77 billion, respectively.[3] And again, unless effective interventions are developed, those costs will rise dramatically with the increase in the numbers of senior citizens in coming decades.

An Explosion of Knowledge

The good news, in the face of these grim statistics, is that we have made tremendous strides in our understanding of the basic mechanisms of Alzheimer's disease within the last five years, and this new understanding has led to entirely new research paradigms: both for studying the disease in the laboratory and managing it in the clinic.

The first set of discoveries I'd like to discuss have to do with the genetics of Alzheimer's disease. Until 2009, only one genetic variant, APOE -4, had been shown to increase the risk of late-onset Alzheimer's disease. However, with the advent of genome wide association studies (GWAS) and other high throughput technologies, the list of known gene risk factors grew substantially over the next few years, and in 2013, the largest GWAS ever conducted identified a total of 11 genetic risk factors. The research conducted by the International Genomic Alzheimer's Project--a collaborative, international study supported in part by the NIH--strengthens evidence about the involvement of particular pathways in the disease, such as inflammation, lipid metabolism, and amyloid deposition, and also points to entirely new molecular pathways that were not known to be involved.

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[2] Prince M et al. The Global Prevalence of Dementia: A Systematic Review and Metaanalysis. Alzheimer's and Dementia 9: 63-75, (2013).

[3] Hurd MD et al. Monetary Costs of Dementia in the United States. New England Journal of Medicine 368: 1321334, (2013). See also http://www.nia.nih.gov/newsroom/2013/04/nih-supported-study-finds-us-dementia-care-costs-high-215-billion-2010

- Create and maintain an integrated national plan to overcome Alzheimer’s disease and

recommendations by using a high program priority funding process to support investigator-initiated grants on frontotemporal dementia and the vascular contributions to dementia.

Revving Up Research

Research in Alzheimer's disease at NIH today runs the gamut from very basic neuroscience research to cutting-edge clinical trials designed to prevent or treat the disease. In the basic science arena, a major new program that has just begun this year is the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative – referred to by President Obama as the "next Great American Project". NIH is a leading member of this pioneering new venture, and has issued several research solicitations in the past two months that will enable us to develop a deeper understanding of brain function through the creation of new tools capable of examining the activity of millions of nerve cells, networks, and pathways in real time. By measuring activity at the scale of circuits and networks in living organisms, we can begin to translate data into models that will decode sensory experience, motor planning, and, potentially, even memory, emotion, and thought. We believe that successful completion of the BRAIN Initiative will revolutionize the field of neuroscience, providing a foundational platform for major advances in Alzheimer's and other brain diseases.

Another major current opportunity lies in the work of the Alzheimer's Disease Sequencing Project (ADSP), a program supporting large scale DNA analysis for the Alzheimer's disease research community. The ADSP is a collaboration between NIA-funded geneticists and the National Human Genome Research Institute Large-Scale Sequencing Program. Goals of the program are to identify new genes contributing to increased risk of and protection from the disease; to provide insight as to why individuals with known genetic risk factors escape the disease; and to identify potential avenues for therapeutic and preventive approaches. Last December, NIH announced the availability of the first batch of genome sequence data from the ADSP, including whole genome sequence (WGS) data from 410 individuals in 89 families. Researchers can access the sequence data at dbGaP (http://www.ncbi.nlm.nih.gov/gap) or the

Still another example of how NIH-supported research is accelerating

multiple ways. For example, signs that a stroke has occurred are often found in the brains of Alzheimer's patients, and beta-

Each of these studies will rely on the availability of validated biomarkers of disease. Identification and characterization of biomarkers and targets for intervention are the primary goals of the Accelerating Medicines Partnership (AMP), just announced in February 2014. With project management by the Foundation for NIH (FNIH), ten pharmaceutical companies will collaborate with NIH. All data will be made publicly available, and NIH and industry will share in the $230 million cost over five years for the first projects: Alzheimer's disease, type 2 diabetes, and the autoimmune disorders rheumatoid arthritis and systemic lupus erythematosus. For Alzheimer's disease, AMP resources will be used to incorporate an expanded set of biomarkers into four ongoing trials designed to delay or prevent disease, and then evaluate which ones are most effective. AMP resources will also support large-scale, systems biology analyses of brain tissue samples from people with Alzheimer's disease to validate biological targets that play key roles in disease progression, in order to increase understanding of molecular networks involved in the disease and identify new potential therapeutic targets. AMP represents an unprecedented model for pre-competitive collaboration that should substantially accelerate the ability to identify the next generation of drug targets and biomarkers.with -34.9onesllan 2.24 0 Td (-)Tj530.004

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the laser is remotely activated, the proteins respond by turning cells on and off, enabling us to track the cell's function. This technology – known as optogenetics – is being used in animal models of Alzheimer's disease to provide information that will help us to understand functions of the normal as well as the Alzheimer's brain.

This concludes my testimony. I am happy to respond to your questions.