Peter V. Rabins, M.D., M.P.H., received his medical degree from Tulane University School of Medicine and his degree in public health (M.P.H.) from Tulane University School of Public Health. He completed his residency in psychiatry at the University of Oregon. Currently, he is a Professor of Psychiatry at the Johns Hopkins University School of Medicine, where he was the founding director of the Division of Geriatric Psychiatry and Neuropsychiatry. He previously held the Richman Family Chair. Dr. Rabins also has joint appointments in the Department of Internal Medicine and the Bloomberg School of Public Health.

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Alzheimer’s: Looking For Quicker Solutions

George Vradenburg is Chairman of USAgainstAlzheimer’s, which he co-founded in 2010 with his wife Trish and several friends with the stated mission to stop Alzheimer’s disease by the year 2020. Mr. Vradenburg was named by former U.S. Health and Human Services Secretary Kathleen Sebelius to serve on the Advisory Council on Research, Care, and Services established by the National Alzheimer’s Project Act and has testified before Congress about the global Alzheimer’s pandemic. He was appointed by U.K. Prime Minister David Cameron as a member of the World Dementia Council.

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What is the use of living, if it be not to strive for noble causes and to make this muddled world a better place for those who will live in it after we are gone?
—Winston Churchill

• Getting involved in battling Alzheimer’s. I became intimately involved with Alzheimer’s disease shortly after my wife’s mother, Bea Lerner, called at 3 a.m. to complain about a strange man in her house who she feared was there to rob her. My wife Trish and I immediately went to her home to find only one man in the house, her husband. Bea pulled us aside and carefully pointed to her husband, saying, “That’s the strange man. He’s nice, but I don’t know him.” Several years later, Bea died in a nursing home of Alzheimer’s, unable to speak, to move, to recognize her daughter.

I am a lawyer by education, training and profession. My career had included senior positions at CBS, FOX and AOL/Time Warner before finally stepping away from the everyday work world in 2003. Since the death of my mother-in-law, one of my goals has been to do something positive to help solve the Alzheimer’s disease problem through my own time, expertise and hard work.

A lifetime of experience in the law and in policy matters has given me a deep appreciation for the power of Washington policy makers to effect positive change in the world. So, I, along with Trish, set out to get Washington to focus on Alzheimer’s through political engagement and a National Strategic Plan for Alzheimer’s—a “moonshot” goal—that would include substantial and sustained strategic investments in outcomes-oriented research, improved incentives for innovative private-sector drug development, and increased Washington awareness of the scope, scale and urgency of dealing with Alzheimer’s.

In our initial efforts, at the behest of the Alzheimer’s Association, we launched a
The birth of USAgainstAlzheimer’s. It wasn’t long, however, before both Trish and I became impatient and upset about the lack of urgency and passion in the Alzheimer’s movement, so in 2010 we started USAgainstAlzheimer’s, with the goal of working with industry, scientists and patient groups to find a cure for Alzheimer’s. We wanted to mimic the enormous energy of the AIDS movement from the 1980s and 1990s, where we felt there had been a fierce passion and dynamism, along with a shared urgency, for finding solutions to that deadly disease.

Alzheimer’s lacks the advocacy movement analogous to those for AIDS and breast cancer. What we wanted to engender with USAgainstAlzheimer’s was a “We are all in this together” attitude (hence the emphasis on “us” in our name), a requirement, we felt, for helping to find a cure.

The problems in getting things done in a timely fashion in the world of Alzheimer’s. If we are going to make meaningful progress against Alzheimer’s, however, organizations and individuals are going to have to become bold and take risks that add the energy and innovation that government action alone can’t deliver. We can begin by acknowledging that Alzheimer’s remains dramatically underfunded. Each year Congress invests $5.7 billion in cancer research, $2 billion in research on cardiovascular disease, and $3 billion in HIV/AIDS research. But Alzheimer’s, which is more
costly to the nation than cancer, heart disease or HIV/AIDS and one of the nation’s top killers, receives less than $600 million from the National Institutes of Health, which is less than one-half of 1 percent of the cost of care.

The 2015 government-spending package included an increase of $25 million for the National Institute on Aging (NIA), with an expectation that much of the funding would support additional research into Alzheimer’s and dementia. The increase follows a similar $100 million bump included for fiscal year 2014. But it is not nearly enough.

We must escalate the battle against this tragic disease. Because Alzheimer’s is a cancer-size problem, it needs a cancer-size response. The federal government must take the lead by dramatically increasing research funds and mobilizing collaboration between academic research and the pharmaceutical and biotech industry. Until that happens, we’ll continue to watch in horror as this disease engenders untold suffering on American families and claims an increasing number of friends, family and loved ones, including presidents and prime ministers.

• **More efficient Alzheimer’s disease drug trial designs.** Alzheimer’s drug trials are long, costly and risky. Because of uneven application in participant recruitment, at least 20 percent of the patients participating in the trials of experimental drugs don’t even have Alzheimer’s. And, as the field seeks to intervene earlier and earlier in the disease process, how are we going to recruit persons without symptoms and measure the effectiveness of an experimental drug in that population?

Alzheimer’s is an epidemic that not enough people are talking about in this country. If we don’t address the barriers in accelerating translation of innovation to therapies for patients, we will not come up with therapies. During 2014, the Global CEO Initiative on Alzheimer’s Disease (CEOi), a group of leading global companies committed to stopping the disease, began the development of an innovative, standing global trial-ready platform to reduce clinical trial cycles by at least two years and to increase trial efficiency by more than 20 percent. This work is now advancing with energy and momentum across Europe and in Canada as well as the United States. I am proud to serve as the convener of the CEOi.

In November 2014, CEOi organized a two-day international meeting in Lausanne, Switzerland, to discuss a change in the global regulatory paradigm in order to evaluate innovative medicines designed to prevent, not just treat, the symptoms of Alzheimer’s. Doing so will provide incentives to industry to increase their investment in the translation of innovative research into effective therapies for the prevention of Alzheimer’s disease and other dementias.

The Lausanne meeting provided a unique opportunity for governments, interna-
tional organizations, regulators, leading researchers and the pharmaceutical industry to examine the challenges and opportunities in Alzheimer’s and to encourage a move for greater innovation and collaboration—we all need to share responsibility for the solution to our shared problem.

I am confident that the meeting will form the basis for a continuing dialogue among all stakeholders regarding the path forward in the development of safe and effective therapies.

• The Brain Initiative. While endorsing President Obama’s BRAIN Initiative and the goal of the National Plan to Address Alzheimer’s Disease that calls for preventing and effectively treating the disease by 2025, the stated goal of USAgainstAlzheimer’s is stopping Alzheimer’s by 2020.

Although we support the national plan and its goals, we believe, as most every family touched by Alzheimer’s disease believes, that preventing and effectively treating Alzheimer’s by 2025 is simply too long a wait for millions of Americans. There are promising drug candidates in late stage clinical testing that will, if successful, deliver by 2020 a means of slowing or deferring Alzheimer’s symptoms. By voicing the urgency felt by so many families, USAgainstAlzheimer’s is pressuring researchers, regulators and industry to do all in their power to make that happen.

• Alzheimer’s philanthropy in the United States. Our hope for near-term change in Alzheimer’s research lies not just with government and industry, but also with American philanthropy. Budget cuts have left the nation’s researchers scrambling for jobs. Not only are labs closing, but young researchers, the lifeblood of science for decades to come, are moving abroad in search of employment.

Even in the face of fiscal stress on government budgets, I believe that wealthy Americans are willing to commit resources to help find a cure for Alzheimer’s disease. As I have discovered over the years, it just takes some convincing. The suffering of acquaintances or family members moves some donors, as it did for one wealthy person from the tech community who recently reached out to me about investing $1 billion for Alzheimer’s research. One of the challenges is looking at the product life cycle of the research/commercialization/biomarker/infrastructure/regulatory science/market access landscape and locating the optimal points for investment so it achieves the most good. I look forward to the creation of a “fund of funds” that can offer to other fierce philanthropists just such an investment advisory service.

Here’s just one important example of an innovative funder’s broad approach to solving Alzheimer’s. In order to help innovative drug researchers move their studies along so they can get the funding to go from laboratory to human trials and eventually grab the interest of a major pharmaceutical company, the family of Ray Dolby, the
founder of Dolby Laboratories who died of Alzheimer’s in 2013, has invested in PharmatrophiX, a Menlo Park, California, biotech company developing small molecules targeting mechanisms underlying Alzheimer’s and other neurodegenerative disorders.

The Dolby family also earmarked $500,000 for Cortexyme, a San Francisco company that believes a specific, undisclosed pathogen is tied to neurodegeneration caused by Alzheimer’s. In addition, the family has donated $21 million to fund the Ray Dolby Brain Health Center at California Pacific Medical Center in San Francisco, and the Dolby Foundation has recently contributed to the initiative to improve the clinical trials infrastructure noted above.

Most importantly, USAgainstAlzheimer’s is hoping to start a conversation about Alzheimer’s and other dementias, to raise consciousness about a health crisis that is creating a soon-to-hit tsunami in this country and around the world. Without a cure or the ability to delay the onset of this debilitating disease, we will all suffer the loss of an extraordinary standard of healthcare in our country—the Medicare/Medicaid system will go bankrupt, our economy will be impacted, and the loss of millions of bright and inspiring Baby Boomers will leave us bereft on so many levels.

Join me in fighting back. Let your voice be heard!

For more information about USAgainstAlzheimer’s, go to www.usagainstalzheimers.org, or contact USAgainstAlzheimer’s, 1101 K St. NW, Suite 400, Washington, DC, 20005, tel.: 202-349-3803.
The information contained in Memory Disorders is not intended as a substitute for the advice of a physician. Readers who suspect they may have specific medical problems should consult a physician about any suggestions made.
FROM THE DESK OF
Peter V. Rabins, M.D., M.P.H.

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