

Penny Wise, Pound Foolish: Fairness and Funding at the National Institute on Aging



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Alzheimer's Foundation of America
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The Alzheimer's Foundation of America (AFA), www.alzfdn.org, is a leading national nonprofit organization whose mission is "to provide optimal care and services to individuals confronting dementia, and to their caregivers and families—through member organizations dedicated to improving quality of life." Today, AFA unites more than 1,600 member organizations from coast to coast that provide hands-on programs and services, including grassroots nonprofit organizations, healthcare facilities, government agencies, public safety departments and long-term care communities. Advocating for meaningful public policy on behalf of individuals with Alzheimer's disease and related illnesses and their family caregivers is an important part of AFA's mission. AFA was the only national Alzheimer's organization to support the Patient Protection and Affordable Care Act and has also been active in efforts such as: advising on the "Caregiver Initiative" included in the February 2010 annual report for the Middle Class Task Force, chaired by Vice President Joe Biden; doubling federal appropriations for the Missing Alzheimer's Disease Patient Alert Program; organizing more than 100 national and local organizations in support of the National Alzheimer's Project Act; and co-facilitating public policy activities around health reform implementation for Leaders Engaged in Alzheimer's Disease (LEAD), a network of more than 30 members and organizations dedicated to increasing awareness of Alzheimer's disease and accelerating solutions to the Alzheimer's disease crisis.

This report was authored by Susan Peschin, MHS, AFA's vice president of public policy. It was edited by Carol Steinberg, AFA's executive vice president. Research assistance was provided by Shane Austin, AFA's public policy specialist.

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Introduction

The National Institute on Aging (NIA), one of the 27 institutes and centers of the National Institutes of Health (NIH), leads the national scientific effort to understand the nature of aging in order to promote the health and well-being of older adults, whose numbers are projected to escalate in the coming years due to increased life expectancy and the aging of the baby boom generation. The number of people age 65 and older will more than double between 2010 and 2050 to 88.5 million or 20 percent of the population; and those 85 and older will increase three-fold to 19 million, according to the U.S. Census Bureau.

Increased investment in preventing, treating or curing chronic diseases of the aging, such as Alzheimer's disease, is perhaps the single most effective strategy in reducing national spending on healthcare. Chronic diseases associated with aging account for more than 75 percent of Medicare and other federal health expenditures.¹

Unprecedented increases in age-related diseases as the population ages are one reason the Congressional Budget Office projects that total spending on healthcare will rise to 25 percent of the U.S. gross domestic product by 2025 from 17 percent today.² Simply put, our nation does not have the luxury of time to address the health research needs of this population.

In stark contrast to the rapidly-rising costs of healthcare for the aging, we as a nation are making a miniscule—and declining—investment in the prevention, treatment or cure of aging conditions. Out of each dollar appropriated to the NIH, only 3.6 cents goes toward supporting the work of the NIA.³ Today, the NIA's percentage of the total NIH budget is at the lowest point since 1990.

Between FY 2003 and FY 2010, scientists saw a series of nominal increases and cuts that amounted to a 14.7 percent reduction in constant dollars for the NIA. In addition, the success rate of grant applications at NIA has declined from approximately 30 percent during the NIH budget doubling—a five-year effort by Congress in 1999 to double the NIH budget—to 17.5 percent in FY 2009, with an 11.8 percent payline⁴;

¹ http://www.fightchronicdisease.org/pdfs/CBO_whitepaperwPFCDback.pdf

² "The Long-Term Outlook for Health Care Spending," Congress of the United States, Congressional Budget Office, November 2007.

³ <http://www.nih.gov/about/almanac/appropriations/index.htm>

⁴ **Success rate versus payline:** **Success rates** are calculated by dividing the number of applications selected for awards by the total number of applications reviewed (if an application is unfunded on the first try and an amended application is received in the same fiscal year it is only counted once). Success rates are therefore highly dependent on the number of applications that are submitted to the NIH for review, and may fall significantly in years when the number of applications increases, but the funds available to fund grants does not. Generally, the NIH uses success rates in reference to research grants, research project grants or specific types of grants considered for funding in a particular fiscal year. Since these numbers are generated for a large aggregation of applications and awards, they typically have little relationship to percentile paylines established by the individual NIH institutes or centers. In fiscal year 2010, the NIH reported that the NIA reviewed 2,127 applications and awarded 309, for a success rate of 14.5 percent. Conversely, each institute calculates its **payline**—which is a percentile-based funding

payline is a funding cutoff point determined by each institute. In FY2010, the announced NIA payline is eight percent.⁵ The modest increases in the NIA budget have not kept pace with the rate of inflation, resulting in the funding of fewer grants and an average 18 percent cut in the amount of competing Research Project Grants (RPGs). While the cost of doing research on diseases and conditions of aging has increased over time and while scientific discoveries have been significant, the underinvestment in these diseases has created a grave and growing threat to American families and our healthcare system, as well as a substantial risk that geriatric researchers will move on to other areas of science with greater prospects for funding.

Alzheimer's disease and related dementias are a particularly dramatic example of the crisis ahead. The NIA reports that as many as 5.1 million Americans currently have Alzheimer's disease, and the number is projected to rise significantly in the coming years as the population ages; the risk of Alzheimer's disease increases with age.⁶ In addition, more and more families and caregivers will bear the physical, financial and emotional toll of this disease. The growing number of people affected by Alzheimer's disease and the rapidly-rising costs associated with the disorder will put a heavy economic burden on families, businesses and government.

As the lead NIH institute on Alzheimer's disease research, including genetic, biological, clinical, behavioral, social and economic studies, the NIA will not be able to move toward a breakthrough without a substantial investment in this disease state.

The Alzheimer's Foundation of America (AFA) and 20 partnering organizations⁷ are seeking a minimum \$1.4 billion, an increase of \$300 million, in the FY 2012 NIH budget for the NIA. This funding is the minimum essential to sustain the research needed to make progress in attacking the chronic diseases that are driving massive increases in our national healthcare costs. That level of funding would make the NIA's

cutoff point—by taking into consideration the total number of applications assigned to it as a whole and in some cases to specific scientific programs, and the average cost of awards. The resulting payline reflects the amount of money available for competing awards in that specific institute or institute's scientific area. Applications that score within the payline are most likely to be funded. NIA's announced payline of 8 percent in FY2010 means that it paid applications scoring within the first eight percentile points. Some applications that addressed the NIA or NIH priorities (such as for new and early stage investigators) were paid beyond that line.

⁵ This can be attributed to several factors—a decline in the number of small, two-year grants (i.e., R03, R21) awarded and the corresponding increase in five-year grants; the advancement of science to the point where the NIA is supporting more large clinical trials, therefore consuming a larger portion of the budget; and the rise in the costs of R01 grants, attributable to documented inflation in the cost of science.

⁶ <http://www.nia.nih.gov/Alzheimers/AlzheimersInformation/GeneralInfo/>

⁷ Alliance for Aging Research, Alzheimer's Foundation of America, American Association for Geriatric Psychiatry, American Chronic Pain Association, American Federation for Aging Research, American Geriatrics Society, American Pain Foundation, American Society on Aging, Association for Research in Vision and Ophthalmology, Brown University, Center for Aging Services Technologies, Gerontological Society of America, Hospice Foundation of America, National Association of Social Workers, National Hospice and Palliative Care Organization, Parkinson's Action Network, Society for Women's Health Research, The George Washington University School of Nursing, The Simon Foundation for Continence, University of Pennsylvania Institute on Aging, and USAgainstAlzheimer's.

baseline consistent with comparable research initiatives conducted elsewhere under the auspices of the NIH.

This level of commitment is nowhere near the investment required by the scope and the scale of the challenge that Alzheimer's disease presents. In 2010, Alzheimer's disease care costs were estimated at \$172 billion, while the federal investment at the NIH in Alzheimer's disease research is estimated to be only \$469 million.⁸ At NIA alone, \$332.4 million of its \$1.1 billion budget (30 percent) went to Alzheimer's disease research in 2009.⁹

Despite the current funding disparity, there is widespread bipartisan Congressional support to substantially increase Alzheimer's disease research funding at the NIH. The Alzheimer's Breakthrough Act (S. 1492 and H.R. 3286 in the 111th Congress) called for increasing NIH Alzheimer's research funding to \$2 billion starting in FY 2010 and garnered 45 Senate cosponsors and 137 House cosponsors. Additionally, in 2009, the Alzheimer's Study Group, composed of 11 prominent members—including former Supreme Court Justice Sandra Day O'Connor, Nobel Laureate and former NIH Director Harold Varmus, former CMS Administrator and FDA Commissioner Mark McClellan, former Surgeon General David Satcher, and other scientific, professional and policy experts—suggested that “Congress immediately increase funding for Alzheimer's and dementia research at the National Institutes of Health to \$1 billion per year, with commensurate increases for Alzheimer's and dementia programs at other federal health agencies. This increased funding should be from additional appropriations. It should not be through reassignment from other objectives.”¹⁰

If the NIA funding is not significantly increased, we stand to lose a generation or more of young and emerging investigators in aging and Alzheimer's disease. This would be an enormous waste since the NIA is poised to accelerate the scientific discoveries that can be translated quickly into effective prevention and efficient healthcare to reduce the burden of what the Alliance for Aging Research regularly refers to as a “silver tsunami” of age-associated chronic diseases. Breakthroughs can lead to treatments and public health interventions that could delay the onset or slow the progression of costly conditions such as heart disease, stroke, diabetes, bone fractures, age-related blindness, Parkinson's disease and Alzheimer's disease. **From a budgetary perspective alone, such advances could save Americans, society and the government trillions of dollars by the middle of the current century, justifying investments of a magnitude above the minimum \$1.4 billion that we are seeking in the NIA's 2012 budget.**

⁸ Lewin Group for the Alzheimer's Association, *Changing the Trajectory of Alzheimer's Disease: A National Imperative*, May 2010; National Institutes of Health Office of the Budget <http://report.nih.gov/rcdc/categories/>.

⁹ <http://report.nih.gov/rcdc/categories/ProjectSearch.aspx?FY=2009&ARRA=N&DCat=Alzheimer's Disease>

¹⁰ Alzheimer's Study Group, *A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Study Group*, March 2009.

What is the National Institute on Aging and Why Should We Care About It?

The National Institute on Aging (NIA) is part of the National Institutes of Health (NIH)¹¹ and leads the national scientific effort to understand the nature of aging in order to promote the health and well-being of older adults. Congress established the NIA in 1974 to conduct research on aging processes, age-related diseases, and special problems and needs of the aged; train and develop research scientists; provide research resources; and disseminate information on health and research advances. NIA is also the primary federal agency on Alzheimer's disease research.

The NIA has been at the forefront of some of the most important advances in aging research and translational programs, including:

- Development of the drug-eluting coronary stent, used to open arterial blockages in the heart during angioplasty. Nearly two million people worldwide have received these stents, which reduce subsequent narrowing rates to three to six percent.¹²
- The NIA's Diabetes Prevention Program demonstrated that diet and exercise were the most effective ways to reduce the risk of diabetes in high-risk older people. The clinical trial intervention showed a 71 percent reduction in diabetes among participants 60 and older.¹³
- Karlene Ball, an NIA grantee, developed Useful Field of View (UFOV), which is the area where someone can extract visual information at a glance without head or eye movements. Research found that training UFOV can prospectively reduce automobile crash rates by half. Several state Motor Vehicle Departments are using and testing UFOV, and Allstate Insurance Company and State Farm offer discounts with this training.¹⁴
- NIA-funded research led by Mary Tinetti, M.D., of the Yale University School of Medicine found that training clinical staff in falls prevention practices and strategies can help reduce serious falls by nine percent and the need for related medical care by 11 percent among seniors aged 70 and older, reducing the incidence and cost of hospitalizations.¹⁵
- Researchers from the Alzheimer's Disease Neuroimaging Initiative showed that changes in the levels of certain proteins in cerebrospinal fluid may correlate with the risk and progression of Alzheimer's disease. These biomarkers may be used in the future to identify individuals at risk of developing the disease. In addition, measuring amyloid in the brain may prove promising as a diagnostic tool. A

¹¹ The National Institutes of Health (NIH), a part of the U.S. Department of Health and Human Services, is the nation's medical research agency. NIH is made up of 27 institutes and centers (including NIA), each with a specific research agenda, often focusing on particular diseases or body systems.

¹² <http://www.grc.nia.nih.gov/branches/osd/Fact%20Book%202010.pdf>

¹³ <http://www.nia.nih.gov/AboutNIA/BudgetRequests/FitnessNutrition.htm>

¹⁴ <http://www.nia.nih.gov/NewsAndEvents/SOAR/2010Spring/Discovery/drivers.htm>

¹⁵ Tinetti, M.E., et al. Effect of dissemination of evidence in reducing injuries from falls. *N Engl J Med.* 2008 July 17. 359:252-61.

preliminary study linked the presence of high levels of brain amyloid in cognitively normal people to greater risk of later cognitive decline.¹⁶

- NIA-funded clinical trials REACH I and REACH II developed and tested strategies for helping caregivers manage the stress and emotional burden of caring for people with dementia. The first study showed a significant improvement in caregivers' sense of burden, social support, depression and health, as well as in care recipients' behavior problems and mood.¹⁷ The U.S. Department of Veterans Affairs successfully used REACH strategies in a demonstration project with 19 of its Home Based Primary Care programs, which treat frail individuals with dementia and caregivers in their homes, and it is now considering using REACH throughout its system. Additionally, the REACH OUT program at the Administration on Aging is beginning to implement these strategies through local social service agencies.

Aging research is more important than ever before. As the United States experiences a longevity revolution and as baby boomers approach retirement age, these trends are touching off a “silver tsunami” that will double the number of Americans age 65+ to more than 70 million by 2030. As of January 1, 2011, 10,000 people are turning 65 every day—and this incidence will continue for 20 years. By 2030, about one in five persons will be over 65.¹⁸

Age is the single greatest risk factor for disease and a huge cost burden to society. It is estimated that 80 percent of all seniors in the United States have at least one chronic condition and half have at least two chronic conditions. Seven out of 10 deaths are attributable to chronic disease, and chronic disease is also the leading cause of disability.¹⁹ The most common chronic diseases are costing the nation more than \$1 trillion per year—a figure expected to increase to \$6 trillion by the middle of the century.²⁰

Financial services company Standard & Poor's recent report “Global Aging 2010: An Irreversible Truth”²¹ stated:

No other force is likely to shape the future of national economic health, public finances, and policymaking as the irreversible rate at which the world's population is aging ... Standard & Poor's Rating Services believes that the cost of caring for these people will profoundly affect growth prospects and dominate

¹⁶ <http://www.nia.nih.gov/Alzheimers/Publications/ADProgress2009/Summary/highlights.htm>

¹⁷ <http://www.nia.nih.gov/Alzheimers/Publications/ADProgress2009/Summary/highlights.htm>

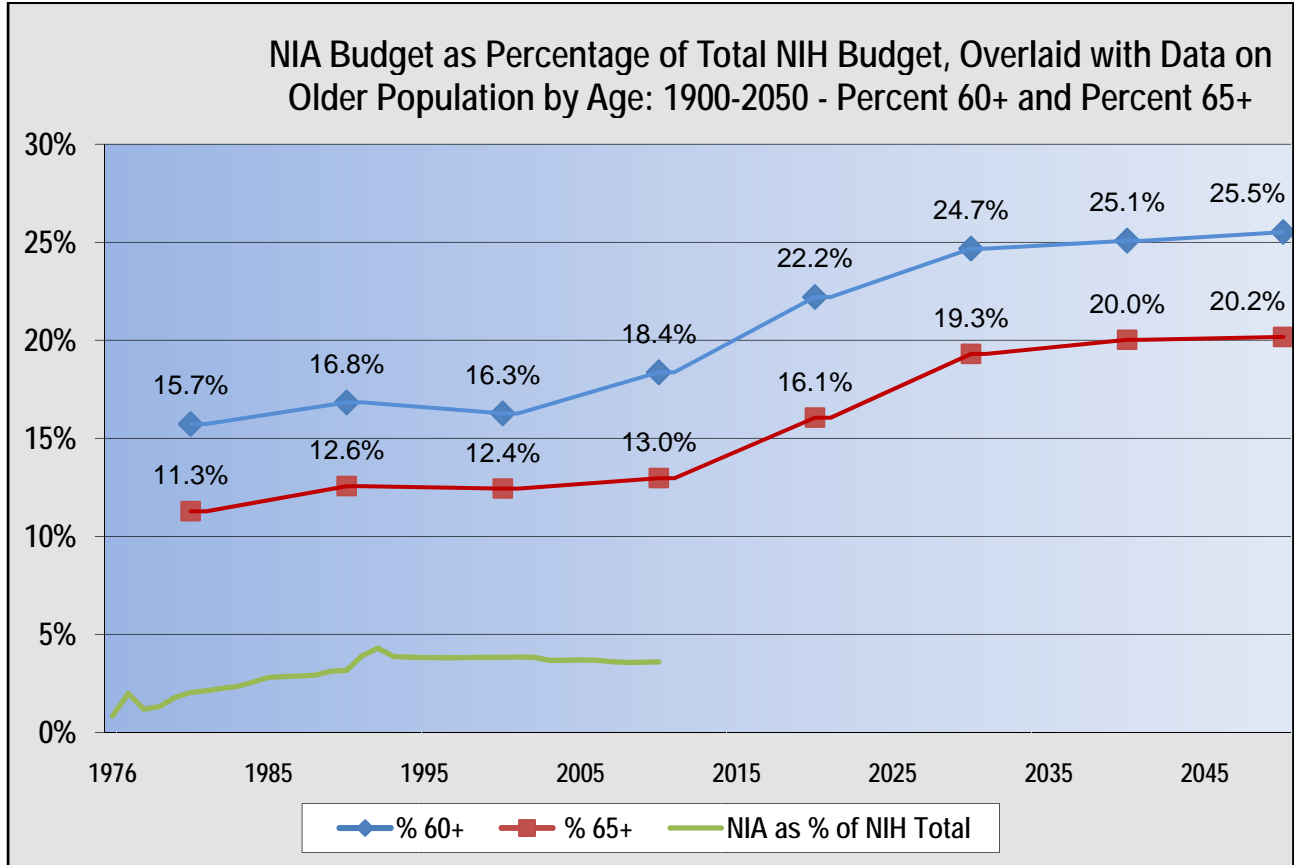
¹⁸ http://mayoresearch.mayo.edu/mayo/research/aging_center/aging_demographics.cfm

¹⁹ CDC and Merck Company Foundation: “The State of Aging and Health in America 2007.” Lynda Anderson, PhD, director, Healthy Aging Program, CDC.

²⁰ Ross DeVol and Armen Bedroussian, with Anita Charuworn, Anusuya Chatterjee, In Kyu Kim, Soojung Kim and Kevin Klowden, “An Unhealthy America: The Economic Burden of Chronic Disease [Executive Summary and Research Findings],” Milken Institute, October 2007.

²¹ Source: Standard & Poor's, “Big Changes in Standard & Poor's Ratings Criteria: Global Aging 2010: An Irreversible Truth”, October 7, 2010.

public finance policy debates worldwide...In our view, the maneuvering room has shrunk and delays in policy implementations may generate additional political, economic and budgetary costs.



Sources: US Census Bureau; <http://www.nih.gov/about/almanac/appropriations/index.htm>

Chart of Percent of Population aged 60+ and 65+, 1900 to 2050 – Overlaid with Data on NIA Budget as Percentage of Total NIH Budget²² The blue line in this chart shows the dramatic projected growth in the percentage of the population age 60 and older, while the red line shows the projected growth in the percentage of the population 65 and older. This chart shows that the percent of the population 60 and older has risen from 16 percent in 1980 to 18 percent in 2010, and is projected to be 25 percent in 2030 and 26 percent in 2050. It shows the percent of the population 65 and older was projected to increase from 11 percent in 1980 to 13 percent in 2010, and is projected to

²² Sources: Projections for 2010 through 2050 are from: Table 12. Projections of the Population by Age and Sex for the United States: 2010 to 2050 (NP2008-T12), Population Division, U.S. Census Bureau; Release Date: August 14, 2008. The source of the data for 1900 to 2000 is Table 5. Population by Age and Sex for the United States: 1900 to 2000, Part A. Number, Hobbs, Frank and Nicole Stoops, U.S. Census Bureau, Census 2000 Special Reports, Series CENSR-4, Demographic Trends in the 20th Century, 2002. Data on NIH and NIA appropriations was obtained from <http://www.nih.gov/about/almanac/appropriations/index.htm>. This table was compiled by the Friends of the National Institute on Aging and builds upon a prior U.S. Administration on Aging-created graph using the U.S. Census data noted.

rise to 19 percent in 2030 and 20 percent in 2050. The green line at the bottom of the chart shows the percentage of the NIH budget that goes to the NIA. In 2010, less than four percent of the NIH budget was allocated to the NIA, the agency charged with the task of making scientific advances on diseases and conditions of aging. Despite this enormous wave of aging boomers who would benefit from NIA-funded research advances that will help them age healthier, today, the NIA's percentage of the total NIH budget is at the lowest point since 1990.

The Impact of Reduced NIA Funding

If NIA funding is not significantly increased, we stand to lose a generation or more of promising researchers in aging and Alzheimer's disease. The November 11, 2010 issue of *Nature*²³ notes that "[a]lthough the funding situation is tight all around for NIH-supported investigators, the NIA is in an exceptional predicament...As both the U.S. and global populations age, the prevalence of chronic diseases such as cancer, heart disease and diabetes will also grow, along with neurodegenerative ailments...The NIA deals with age-related aspects of all of these." In the article, Richard Hodes, M.D., Director of the NIA, said, "If we are less able to fund research—or are perceived to be less able—that will actually drive young and emerging investigators to fields other than aging. That would be a catastrophe at a time when such research is critically important."

In response to a flood of concern from researchers in the field, Dr. Hodes posted an open letter on the NIA Web site in late October 2010 to the NIA-funded community that stated, in part:

In recent months, many of you have expressed increasing concern about the reduced payline and success rates for aging research at the National Institute on Aging (NIA). I recognize the impact that the situation is having on established researchers as well as on the development of younger scientists for the field. I also understand the implications for research at a time when the population is aging, and when studies addressing the problems of aging are critical to individuals and to society. We at NIA recognize and empathize with the struggle that our constrained funding creates for the research community, and feel that it is vital that we do everything we can to sustain the momentum of investigator-generated research in this successful and vibrant field, as we continue to make a difference in health and well-being in later life.²⁴

As the lead federal agency on Alzheimer's disease research, NIA's reduced funding has hit Alzheimer's researchers disproportionately. In a November 29, 2010 blog post²⁵

²³ Meredith Wadman, "Funding crisis hits US ageing research," *Nature*, Volume 468, November 11, 2010, page 148.

²⁴ <http://www.nia.nih.gov/GrantsAndTraining/Hodes2010-10-25.htm>

²⁵ <http://www.usagainstalzheimers.org/blog/the-end-is-near-to-research-not-to-alzheimers>

entitled “The End is Near—to research; not to Alzheimer’s” on the USAgainstAlzheimer’s Web site, Sam Gandy, M.D., Ph.D., Professor of Neurology and Psychiatry (Dual Primaries), Mount Sinai Chair in Alzheimer’s Disease Research, and Associate Director, Mount Sinai Alzheimer’s Disease Research Center, stated:

Many well-known Alzheimer’s scientists of my generation recognize that we have reached the end of an era. We can no longer afford to think primarily about Alzheimer’s. We can no longer, in good conscience, recommend that our trainees plan for a career in Alzheimer’s research unless they can establish their first labs in China, Korea, Europe, Australia, or South America.

I continue to identify myself as an Alzheimer’s researcher, but funding strategy now requires that we come at the problem indirectly. Now we think in terms of how some area with more reasonable funding might relate to Alzheimer’s. Head trauma and Alzheimer’s is now front and center in our plans, for instance, because of the military funding opportunities; NIDDK [National Institute of Diabetes and Digestive and Kidney Diseases], where the funding line is at 17 [percent], is also a target because of the link between diabetes and Alzheimer’s. Assuming that we can get NIDDK interested, our chances of funding there are somewhere between five and 17 times better than at NIA.

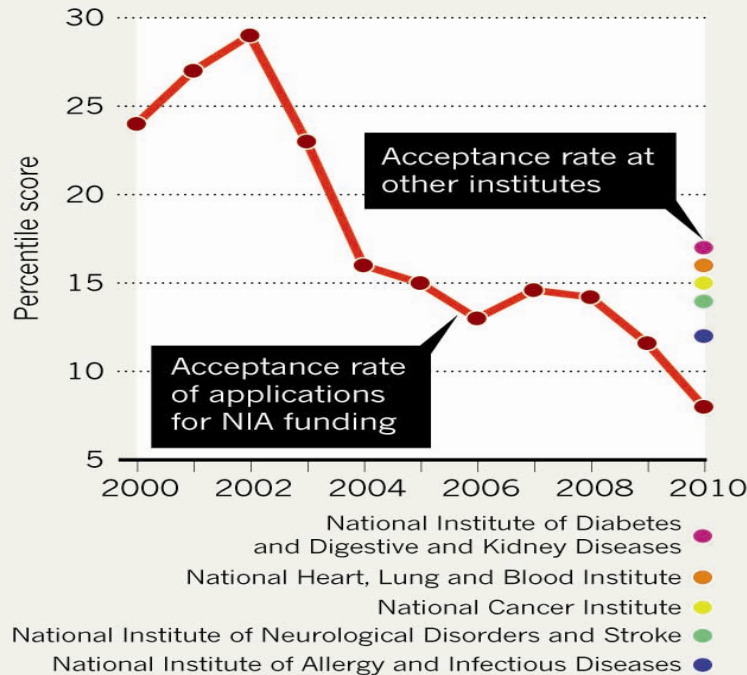
The precipitousness of the decline and the fact that only NIA was crashing were both particularly shocking to me. With the aging of the baby boomers, I always assumed that Congress would step in before the community was decimated, but not so....Is the non-attention of the government to NIA’s crash basically an expression of age discrimination? Among hard choices of what programs to fund and what programs to close, apparently our elders have gotten a “thumbs down.”

My staff and I are targeting 11 grant deadlines over the next few months in order to try to soften the crash while we change our lab’s focus to fit the funding. One tries to “Keep calm and carry on,” but then again, it never occurred to me that the NIA R01 support would go totally bust.

The *Nature* article points out that the NIA payline is inconsistent with comparable research initiatives conducted under the auspices of the NIH. For example, in 2010, a researcher had only an eight percent chance of being approved for funding on a grant application submitted to the NIA, but had a 15 percentage chance of obtaining funding at the National Cancer Institute and even higher at other institutes.

OVER THE HILL

Competition for grants from the National Institute on Aging has become increasingly brutal.



Reprinted by permission from Macmillan Publishers Ltd: Meredith Wadman, *Nature*, Volume 468, November 11, 2010, page 148.

Return on Investment: What We Can Learn From Polio and AIDS

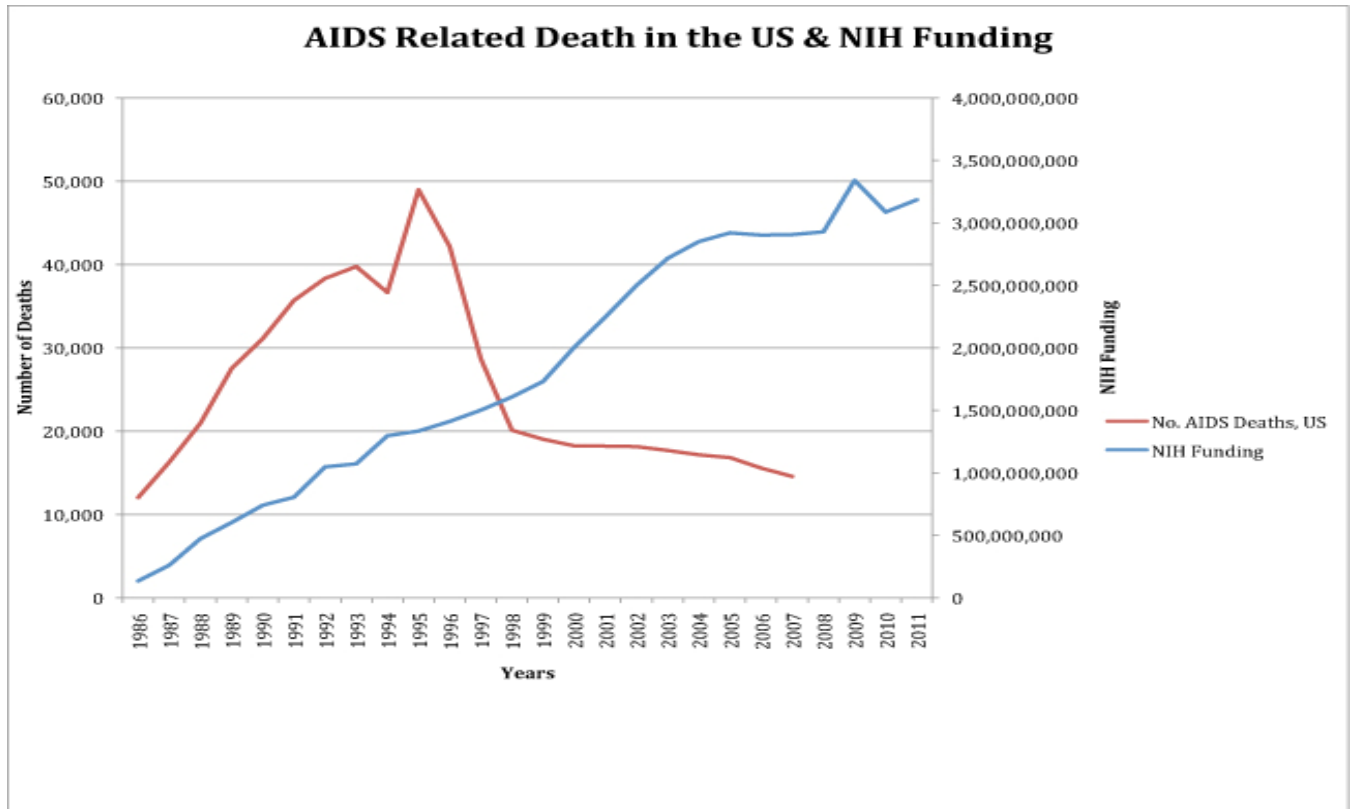
As we have learned from the experience with polio and HIV/AIDS medical research, breakthroughs can have a profound impact on not only reducing mortality and morbidity, but on reducing healthcare costs. For example, the cost-effectiveness of the polio vaccine since 1955 in the United States is estimated at \$180 billion.²⁶ According to former NIH Director Elias Zerhouni, M.D., the \$10 billion invested in basic research in HIV/AIDS between 1985 and 1995 saved \$1.4 trillion in healthcare costs.²⁷ And the extension of life expectancy in the United States from age 50 in 1900 to 78 in 2006²⁸ demonstrates that medical advancements enormously increase national productivity

²⁶ Thompson KM, Duintjer Tebbens RJ. Retrospective cost-effectiveness analyses for polio vaccination in the United States. *Risk Analysis*. 2006;26:1423–1440.

²⁷ BJ Culliton, "Interview: Extracting Knowledge from Science: A Conversation with Elias Zerhouni," *Health Affairs*, 25 (2006): w94-w103.

²⁸ http://www.cdc.gov/nchs/data/nvsr/nvsr58/nvsr58_21.pdf

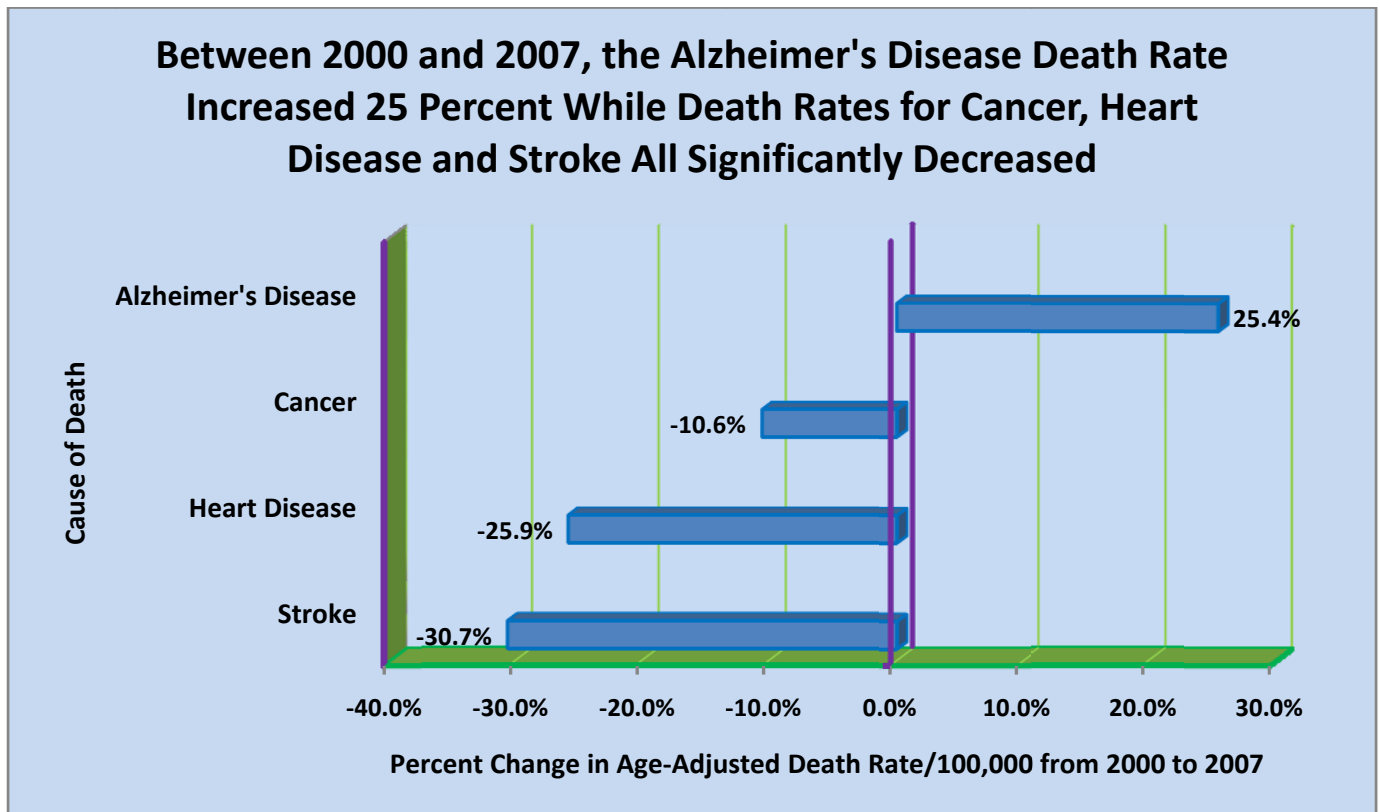
and prosperity. Yet, those benefits can only come about if the NIH makes the needed investments in research aimed at preventing, treating or curing aging-related diseases and extending healthy life.



Source: Stanley B. Prusiner, M.D., based on data from National Vital Statistics Reports and NIH Office of the Budget.

The chart below demonstrates the percent change in rates of death among major chronic disease killers between 2000 and 2007 in the United States. While death rates for cancer, heart disease and stroke have significantly dropped, the death rate for Alzheimer’s disease has increased 25 percent. Factors that contributed to the lower death rates for these diseases may in large part be linked to: NIH-funded research efforts, such as the Framingham Heart Study; highly-effective drugs to lower cholesterol, control high blood pressure, and break up artery-clogging blood clots; formulating approaches to help people make lifestyle changes that promote cardiovascular health; and development of the drug trastuzumab (Herceptin) for breast cancer.²⁹

²⁹ <http://www.nih.gov/about/director/budgetrequest/fy2011testimony.pdf>



Data Source: National Vital Statistics Reports, Vol. 58, No. 19, May 20, 2010.

A recent report, based on a model developed by the Lewin Group for the Alzheimer's Association, demonstrates that even incremental treatment advances in Alzheimer's disease would produce a significant return on investment. According to the report, a treatment breakthrough that delays the onset of Alzheimer's disease by five years and begins to show its effect in 2015 would decrease the total number of Americans age 65 and older with the disease from 5.6 million to four million in 2020; the annual Medicare savings would be \$33 billion in 2020 and climb to \$283 billion by mid-century; and the annual Medicaid savings would increase from \$9 billion in 2020 to \$79 billion in 2050. The study also found that a treatment breakthrough that slowed disease progression in 2015 would result in annual Medicare savings of \$20 billion in 2020 and jump to \$118 billion in 2050, while Medicaid savings would be \$14 billion in 2020 and \$62 billion in 2050.³⁰

³⁰ Lewin Group for the Alzheimer's Association, *Changing the Trajectory of Alzheimer's Disease: A National Imperative*, May 2010; National Institutes of Health Office of the Budget <http://report.nih.gov/rcdc/categories/>.

Setting Funding Priorities

More than a decade ago, in response to a request from Congress, the Institute of Medicine (IOM) developed a study, “Scientific Opportunities and Public Needs: Improving Priority Setting and Public Input at the National Institutes of Health,” that reviewed the NIH's research priority-setting process and made recommendations for possible improvement. The IOM committee considered the factors and criteria used by the NIH to make funding allocations; the process by which the funding decisions are made; the mechanisms for public input; and the impact of Congressional statutory directives on funding decisions. Among other recommendations, the study suggested:

...there is never as much funding as is needed to address all important health problems and pursue all research opportunities or as much funding as NIH's supporters would like it to have. Choices must be made and priorities must be set. Priorities are not only driven by a scarcity of resources. They are also affected by health emergencies and epidemics, **demographic trends affecting health, such as the aging of the population** or changing patterns of tobacco and alcohol use, and new opportunities in science stemming from research advances or better research instruments.³¹

On June 15, 2010, NIH Director Francis Collins, M.D., was called to testify before the House Energy and Commerce Subcommittee on Health at a hearing on the “National Institutes of Health in the 21st Century.” Dr. Collins invoked the aging and Alzheimer’s disease issue several times throughout both his initial testimony and during the question and answer section of the hearing:

At NIH, we discuss probably just about daily, are we getting our priorities right? The factors that go into that are numerous and they do change over time. Certainly the burden of a disease has to be a major consideration. I mentioned Alzheimer’s in my opening statement particularly because of the concern about the burden this disease places on people today and that it may place on people tomorrow. And if we certainly need breakthroughs in a disease, Alzheimer’s [is on] that list...

There are 30 drug trials that are either in place or getting ready to go into action in terms of Alzheimer’s approaches. So, there is a lot of activity here, but I share the sense that this is a time bomb. I mean, it’s already upon us, but it’s getting worse if we don’t come up with better strategies for prevention and treatment in the future.

Typically, the advocacy organizations within aging and Alzheimer’s disease have supported increases to NIH funding in general, following John F. Kennedy’s philosophy

³¹ Scientific Opportunities and Public Needs: Improving Priority Setting and Public Input at the National Institutes of Health Committee on the NIH Research Priority-Setting Process, Institute of Medicine. ISBN: 0-309-59195-3, 136 pages, 6 x 9, p. 29 (1998) <http://www.nap.edu/catalog/6225.html>

that “a rising tide lifts all boats.” However, advocacy organizations in aging and Alzheimer’s disease realize now that such a philosophy has left NIA funding falling further behind other institutes; and thus the time has come—on the verge of the “silver tsunami”—to call for a “bigger boat” for aging diseases.

On September 27, 2010, more than 20 organizations, including AFA, signed a letter to President Obama and the Office of Management and Budget (OMB) requesting a minimum \$1.4 billion, an increase of \$300 million, in FY2012 funding in the NIH budget for the NIA. The letter was soon followed by an in-person meeting with OMB and Capitol Hill briefings to highlight the work of the NIA. On December 17, 2010, AFA and a number of other organizations met with NIH Director Collins and delivered a letter of support for increased NIA funding that was signed by 436 aging and Alzheimer’s disease researchers, educators and clinicians.

Policy Recommendation and Conclusion

AFA and 20 partnering organizations are seeking a minimum \$1.4 billion, an increase of \$300 million, in the FY 2012 NIH budget for the NIA. This funding is the minimum essential to sustain the research needed to make progress in attacking the chronic diseases that are driving massive increases in our national healthcare costs. That level of funding would make the NIA’s baseline consistent with comparable research initiatives conducted elsewhere under the auspices of the NIH.

Interestingly, the typical approach of addressing one disease at a time has helped to increase life expectancy, but it has been largely ineffective at dramatically improving the way people age. In addition to research targeted at the diseases of aging, the NIA seeks to understand the basic biological mechanisms of aging itself. Leaders in the field of aging science whose research has been funded by the NIA have identified several processes that underlie aging, such as: inflammation (linked to cancer, heart disease and various forms of dementia); cellular decline and replacement (aging tissue cannot regenerate and repair as well, such as with osteoporosis, sarcopenia, and the age-related degeneration of joints and spinal discs); and stress response. These areas of investigation are just now showing promise to increase the power we have to address the leading public health challenges of our time. If these scientists can better understand how to modify the basic biological processes linked to a person’s overall decline in function and predisposition to disease, we can improve the resilience of all organ systems, and the same diseases, disabilities and declines would occupy a smaller proportion of a person’s lifetime and increase the number of productive, healthy years.

We do not yet have the knowledge needed to predict, preempt and prevent the broad spectrum of diseases and conditions associated with aging. We do not yet have sufficient knowledge about disease processes to fully understand how best to diagnose and treat diseases and conditions of aging, nor do we have the necessary

knowledge about the complex relationships among biology, genetics, and behavioral and social factors related to aging. We do not yet have a sufficient pool of new investigators entering the field of aging research. Bold, visionary and sustainable investments in the NIA will make it possible to achieve substantial and measurable gains in these areas sooner rather than later, if not too late.