Statement of
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Before the
Special Committee on Aging
United States Senate

March 25, 2009

Chairman Kohl, Ranking Member Martinez and Members of the Committee. Thank you for the opportunity to return to the Senate Special Committee on Aging to report on the key conclusions we have reached through our work as part of the Alzheimer's Study Group. It is a privilege to release our final report, *A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Study Group*,[1] before a committee that has such a distinguished record of championing those issues that so profoundly affect not just older Americans, but our entire Nation as a whole.

I also want to take this opportunity to thank Senator Susan Collins from this committee. As a co-chair of the Senate Congressional Task Force on Alzheimer's Disease, Senator Collins joined with Senator Barbara Mikulski, Senator Richard Burr, and now Secretary Hillary Clinton on July 11, 2007 to launch the effort that we report on here today.

The issues of Alzheimer's disease also benefit from the tireless and extremely able advocacy of your colleagues in the U.S. House of Representatives. In particular I wish to recognize the generous support of Representative Ed Markey and Representative Chris Smith, co-chairs of the House Congressional Task Force on Alzheimer's Disease, for their support of the work of the Alzheimer's Study Group.

When we testified before this committee on May 14, 2008, Chairman Kohl, we were moved and inspired by the personal stories shared by the members of this committee about the terrible impact of Alzheimer's disease on their families and loved ones. It is, we have learned all too well through our work, increasingly the story of America as a whole. It is not just tragic. It is also a national crisis. And it is a crisis that grows with each year.

And so, we thank you for the opportunity to return before you with a plan and even a sense of optimism. We are convinced by our work that we have real, substantial opportunities to not only provide much more effective care and support for those with Alzheimer's disease and their families, but we also have the opportunity to substantially accelerate the arrival of new therapies that can start to turn the tide against this disease and, in time, defeat it.

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[1] The report can be accessed at: www.alzstudygroup.org.

To that end, the key recommendation reached by the Alzheimer's Study Group is the United States should establish the Alzheimer's Solutions Project to accelerate and focus national efforts, reengineer dementia care delivery, and, ultimately, prevent Alzheimer's disease. This project we propose to you today has three pillars:

1. ***The Alzheimer's Prevention Initiative***: As a national priority, urgently focus on developing the capability to delay and, ultimately, prevent Alzheimer's disease. This capability will depend on the advancement of development science as well as basic research.

2. ***The Alzheimer's Care Improvement Initiative***: By 2012, use value-based payments to reimburse providers for at least 20 percent of health and social services for people with dementia, and for half of these services by 2016. Value-based payments will reward health care and social services professionals for providing the coordinated care dementia patients most need for better health and a higher quality of life.

3. ***The Alzheimer's Public-Private Partnership***: By 2010, establish an outcomes-oriented, project-focused Alzheimer's Solutions Project Office within the Federal Government. Backed by an appropriate scale of funding and through active collaboration with other stakeholders outside the Federal Government, this office will lead the successful implementation of the Alzheimer's Prevention and the Alzheimer's Care Improvement Initiatives, together with supporting efforts.

The human pain and financial burden of Alzheimer's is so great and the potential breakthroughs in science are so encouraging that a "Manhattan Project," "Apollo Project," or "Human Genome Project" approach to ending Alzheimer's is more than justified.

The Alzheimer's Solutions Project is in the best American tradition of solving a big problem with a big vision and a big effort. A public-private partnership is the best collaborative approach to achieve that vision as rapidly as possible.

It is the combination of, first, the scale of the crisis and, second, the breadth of the new science which makes this focused, intense investment and project management approach worth implementing.

The Scale of the Alzheimer's Crisis

First, the scale of Alzheimer's as a crisis is something that is vivid and real to individuals and families dealing with the disease but because of its very nature has been consistently underestimated in our public policy.

Consider these facts, principally drawn from the Alzheimer's Association's report, *2009 Alzheimer's Disease Facts and Figures*:

- Every 70 seconds someone in America develops Alzheimer’s disease—by 2050 someone will develop Alzheimer’s every 33 seconds.
- 5.3 million Americans currently suffer from Alzheimer’s—one-in-eight Americans over 65 and almost one-in-two over 85.
- 10 million baby boomers will develop the disease.
- It is a family disease—9,900,000 caregivers provide 94 billion hours of uncompensated care per year.
- Healthcare costs for people with Alzheimer’s disease are three times greater than for people with other diseases.
- In 2005, Medicare spent $91 billion on beneficiaries with Alzheimer’s and other dementias and is projected to spend $189 billion by 2015.
- Given the present trends Alzheimer’s will cost Medicare and Medicaid a projected $19.89 trillion between 2010 and 2050.
- Because people tend to get Alzheimer’s later in life, even a delay has a significant effect in lowering costs. A five year delay of onset would save $8.51 trillion over that same period.
- The CDC lists Alzheimer’s disease as the 6th leading cause of death.
- Today there is no cure, no disease-modifying treatment, and no prevention.

There is no single breakthrough that would do more to lower the cost of entitlements than preventing the onset of Alzheimer’s disease.

In the early 1950s, more than 50,000 Americans were infected with Polio each year. Within years of the licensing of the Salk vaccine in 1955, Polio was effectively eliminated in the United States. An Alzheimer’s preventive would dramatically overshadow even that great scientific victory.

More importantly, there is no single breakthrough that would do more to improve the quality of life of older Americans and more to relieve their family’s and loved ones of pain and worry than to develop a breakthrough in treating or delaying the onset Alzheimer’s.

The Scale of the Science and Research

Second, the exciting opportunity to create the capability to prevent Alzheimer’s is created by the fact that the scale of the need in Alzheimer’s is being matched by the scale of the scientific breakthroughs in our understanding of the human brain.

The enormous increase in our understanding of the brain creates a genuine possibility of “a world without Alzheimer’s” – a view widely shared by leading researchers themselves. In just the past several weeks, almost 200 leading Alzheimer’s research scientists have endorsed the goal of developing the capability to prevent Alzheimer’s by 2020.

However, this goal is only ‘realistic’ if it is pursued realistically.

Tragically, the gap today between scientific potential and scientific resources is enormous. This gap ensures unnecessary suffering and unnecessary costs.

The efforts to develop the new knowledge and then to translate it into new medicines and new therapies are fragmented and underfunded. Mechanisms for sharing new knowledge are stunningly slow and inadequate. For example, the Institute of Medicine has estimated that it takes up to 17 years for a new breakthrough to reach every doctor. This applies to Alzheimer's fully as much as any other disease.

Thus even when the new science leads to new solutions, millions may suffer unnecessarily for years because the current health communications systems are so inadequate.

Every day that we fail to invest in the new science is a day Americans suffer unnecessarily. Today much more money is spent simply treating the complications that arise from Alzheimer's than is invested in developing a cure, better treatments or improved approaches to care.

What we need are a much larger investment in science, a strategy for coordinating the research, mechanisms for accelerating the translation of breakthroughs into practical treatments, and much better ways to reward those who deliver valuable care.

The Alzheimer's Solutions Project should be seen as both the biggest single humanitarian opportunity and the biggest single entitlement savings opportunity in America today.

The Alzheimer's Solutions Project fits both the human and fiscal needs of the American people in the next generation.

Steps to a Successful Alzheimer's Solutions Project

In the following report, the Alzheimer's Study Group has proposes a series of consensus recommendations to address these and other issues.

Immediately below are 16 specific steps, inspired by the report's consensus recommendations, that we, the co-chairs, believe will have the largest impact on our national effort to end the Alzheimer's crisis:

1.We encourage President Obama to make a major speech focused on communicating the facts of Alzheimer's to the American people and sharing with them the opportunity for an historic breakthrough that would improve the quality of life of millions of Americans and would provide help for people around the world. In this speech the President should outline the nature and structure of the Alzheimer's Solutions Project and urge Congress to adopt the Project as a major goal for the Nation.

2. Congress should pass implementing legislation to create a public-private partnership for the prevention of Alzheimer’s and to implement better care models. This legislation should include a fundamental change in the science budgeting process. To reach a solution as quickly as possible, the public and private sectors must work together cooperatively.

3. The annual budget cycle based on immediate constraints should be replaced for Alzheimer’s research with a new model based on the scale of potential savings. If there is already a projectable $19.89 trillion dollar federal expenditure for Alzheimer’s over the next generation then the scale of research investment ought to be measured against the money it will save rather than against other federal expenditure it would crowd out in a static budget. Seen in this light the logical upper bound for an investment budget to find an Alzheimer’s solution is the amount scientific research could intelligently use for the foreseeable future. An annual public-private Alzheimer’s research assessment (including the basic science in math, physics and chemistry which powers many of the breakthroughs in understanding the biology of the brain) should produce a five-year investment strategy which should be funded through a new generational budget outside the traditional budget limits. As National Institutes of Health Director Elias Zerhouni has testified to Congress, the $10 billion invested in basic research on HIV/AIDS between 1985 and 1995 saved $1.4 trillion in healthcare expenditures, a return on investment of 140-to-one. The prospects are that Alzheimer’s research will pay dividends that dwarf those on HIV/AIDS because the scale of the challenge is so much bigger. The choice for our generation is not whether or not to spend the money on Alzheimer’s. The choice for our generation is to invest the money early and save a lot of lives, pain and money later or to be foolishly cheap in the short run, minimize breakthroughs and maximize pain, suffering and cost.

4. Public investment in the Alzheimer’s Solutions Project should be financed through the public sale of tax-exempt bonds. The bonds would be repaid through a sinking fund. Contributions to the sinking fund would be paid into by the Federal government as a percentage of the savings to the Federal Government that would follow the development of the capability to prevent Alzheimer’s.

5. The President should appoint a new Chief Executive Officer to lead the public-private Alzheimer’s Solutions Project. This CEO would report annually on the progress of the Alzheimer’s Solutions Project and the steps necessary to maximize the speed of its completion.

6. The Congress should establish a Joint Committee on Alzheimer’s Disease with unique authorizing and appropriating authority. Members of the Committee would be drawn from the appropriate appropriations and authorizing committees of the House and Senate. This Committee would have oversight of the Alzheimer’s Solution Project and would propose such legislation and such appropriations as needed for its successful completion. The Committee would be disbanded when the three objectives for Alzheimer’s had been developed and implemented.

7. Create a new public-private Alzheimer Solutions Project Advisory Committee with representation from research, treatment, private industry, families, and government. The Advisory Committee would highlight bottlenecks and opportunities and would provide an independent judgment on the effectiveness of the Alzheimer's Solutions Project and the steps needed to accelerate its completion. Annually the Advisory Committee would issue a public report on progress, problems, and opportunities.

8. A public-private Alzheimer's Roadmap for Research and Development should be developed with a five year horizon and an annual update. The dramatic increase in research resources we are proposing should be matched by a systematic improvement in the ability to manage those resources in a coherent manner. This metrics-driven approach has proven its potential again and again. The achievement-oriented focus of the Manhattan Project, the Apollo Project, the Human Genome Project and the extraordinary speed of development in combating HIV/AIDS all stand in stark contrast to the highly decentralized and researcher—rather than research—centered model which has characterized much of the modern government funding process. We believe the potential for preventing Alzheimer's requires a much more sophisticated overview of research opportunities, much more transparency in research information dissemination and a more team focused and long term investment focused approach.

9. Biopharmaceutical research on preventive, disease-modifying and risk-reducing Alzheimer's therapies should be provided incentives equivalent to those in the Orphan Drug Act to maximize investment in new breakthroughs. Scientific research only reaches its full impact in helping people when it is translated into usable medications and usable technologies. Today the complexity of testing medicines for the brain has led to a substantial private sector underfunding of the very translational research that is needed. Furthermore the upcoming struggle over payment for drugs will further discourage investment in medications for Alzheimer's at the very time when we need to be deepening and accelerating the research. Placing Alzheimer's research under provisions equivalent to the Orphan Drug Act would attract a new generation of capital investment in seeking more effective medications.

10. A fundamental reform of the Food and Drug Administration process as it relates to approving drugs relating to Alzheimer's disease is vital. There are very useful proposals for saving as many as six to eight years of the approval time through sophisticated new approaches. These should be thoroughly explored. Every year lost in regulatory bureaucracy is a year of pain, suffering and cost for millions of individuals with Alzheimer's and the loved ones who are caring for them. Streamlining the regulatory process for approval is as important as any single step in getting new medications to help those who need them.

11. As a part of this more focused investment strategy, a series of Comprehensive Alzheimer's Disease Centers should be. Advancing the model established by the National Cancer Institute and the existing Alzheimer's Disease Centers, the objective is to streamline and broaden the scope of activities to include research on interventions, diagnosis, imaging, prevention trials, and other longitudinal studies that require long-term

support. There is an increasing need to identify individuals at high risk of AD for prevention trials and very early in the course of their illness for clinical trials of disease modification. The enhanced Centers Program will accelerate the development of knowledge needed to improve care, delay onset and ultimately prevent the occurrence of the disease.

12. New methods of paying for the care of individuals with Alzheimer's must be developed based on the straightforward premise of paying providers for delivering value to patients and their families. The current Medicare Fee-for-Service system actually discourages doctors from testing to see if their patient has Alzheimer's. Treatment, care management and care coordination are so underfunded that doctors find themselves burdened with liabilities without compensation. The result of the current system is consistent under diagnosis and under reporting of Alzheimer's, and the neglect of treatments and support that could immediately result in significantly improving the quality of life for those with Alzheimer's and their families. New models of payment based on value created, rather than services rendered (whether needed or not), need to be developed so doctors and other health provides will have adequate compensation for dealing with a complex, slowly progressing disease.

13. Because Alzheimer's takes effect over a very long time and often involves many other diseases (co-morbidities) and requires the collaboration of a number of care providers, a special effort should be made to develop electronic health records for individuals with Alzheimer's. This will lead to substantial savings in both time and money and to a substantial improvement in care. The first step might be to identify those institutions which have already developed such electronic health records for their own use.

14. The National Library of Medicine, the Institute of Medicine and the Agency for Health Research and Quality should collaborate with private sector systems to develop a real-time internet-based dissemination system for researchers, doctors, individuals with Alzheimer's and care giving families. The goal should be to translate new opportunities into available knowledge within weeks rather than years and to allow every concerned citizen to access the knowledge base. This Rapid Learning Network for Alzheimer's would revolutionize the transmission of knowledge to those who most need it.

15. A national online Registry for Early Detection and Treatment of Alzheimer's should be established for three reasons. First, to get doctors in the habit of looking for early signs of the disease (something many actually reject doing today). Second, to encourage individuals with Alzheimer's to make themselves available for scientific trials as new knowledge leads to new opportunities. The time and cost savings of developing a pool of willing research volunteers would more than pay for the cost of the Registry. Third, to enable the transmission of new knowledge to every person who registers and their caregivers so we can dramatically accelerate the translation of new knowledge to new treatments.

16. New community-based programs should be developed to take maximum advantage of the new technology and new communications systems to help caregivers and individuals with Alzheimer's cope with the diseases challenges with all the assets and capabilities a modern society can develop. Those who are willing to care for their loved ones should not be abandoned to obsolete technologies and inadequate information. We can do much better.

These 16 steps would represent one of the most comprehensive solution oriented efforts in American history.

Taken together these 16 steps meet the challenge of Alzheimer's and offers hope to millions both today and for the future.

Thank you.