



Testimony of Matthew Baumgart, Senior Director of Public Policy of the Alzheimer's Association
The Global Challenge of Alzheimer's: The G-8 Dementia Summit and Beyond

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Good morning Chairman Smith, Ranking Member Bass, and members of the Subcommittee. Thank you for the opportunity to testify on the global challenge of Alzheimer's disease and the opportunity for global progress with the upcoming G8 Summit on dementia research.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. Our mission is to eliminate Alzheimer's disease and other dementias through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. As the world's largest nonprofit funder of Alzheimer's research, the Association is committed to accelerating progress of new treatments, preventions, and ultimately a cure. Through our funded projects and partnerships, we have been a part of every major research advancement over the past 30 years. And, through our work to enhance care and provide support for all those affected by Alzheimer's, we have helped millions of individuals living with the disease and their families.

The Global Impact of Alzheimer's

Alzheimer's disease is a global public health crisis. This crisis is placing – and will increasingly place – an enormous strain on families, the health care system, and government budgets of nations around the world. Current estimates indicate that about 36 million people worldwide are living with dementia, and when we reach the middle of the 21st century, there will be 115 million people living with dementia. Dementia has been creating an enormous burden in North America and Western Europe. Increasingly, that burden is spreading to low- and moderate-income countries. Between 2010 and 2050, the number of people with dementia in low- and moderate-income countries is expected to quadruple – and the proportion of worldwide dementia cases in low- and moderate-income countries will increase from 58 percent to over 70 percent.

In its 2010 annual report – *The Global Economic Impact of Dementia* – Alzheimer’s Disease International (ADI) reported that the global cost of dementia totaled \$604 billion in 2010, amounting to one percent of global Gross Domestic Product (GDP). If dementia were a country, it would be the 18th largest global economy.

Research shows that most people currently living with dementia have not received a formal diagnosis. In the United States, as many as half of the over 5 million individuals with Alzheimer’s have not been diagnosed. And, in India, a study found that nearly 90 percent of those with dementia remain unidentified. In total, ADI concluded in 2011 that as many as 28 million of the 36 million people living with dementia throughout the world have not been diagnosed and therefore do not have access to the treatment, care, and organized support that a formal diagnosis enables.

The global burden of this devastating disease was further underscored in this year’s ADI report on long-term care. The report found that as the world’s population ages, the traditional system of informal care by family, friends, and community will require much greater support. Today, it is estimated that 13 percent of people aged 60 or over require long-term care. Between 2010 and 2050, the total number of older people with care needs will nearly triple from 101 million to 277 million. And people with dementia are a large portion of that number. In the United States, for example, nearly 65 percent of nursing home residents have dementia.

Global Research Efforts

The global Alzheimer’s crisis requires a global response. And while the Alzheimer’s Association is a U.S.-based organization, we are committed to working globally to eliminate Alzheimer’s disease. No single organization can surmount a challenge as great as Alzheimer’s. To help achieve our vision of a world without Alzheimer’s, the Association partners with key government, industry, and academic stakeholders around the world. We believe in the value of collaboration and that it can be the catalyst toward achieving disease-modifying treatments, prevention, and ultimately a cure.

The Association formula for progress rests on four pillars: funding, collaborating with investigators, sharing data, and overcoming barriers to progress. The first pillar is the Alzheimer’s Association International Grant Program. Typically 10 to 15 percent of our grant funds are spent outside the United States. Currently, we fund active grants in 21 countries, and have funded research in 28 countries overall.

The second pillar of the Alzheimer’s Association program is encouraging increased cooperation between scientists. The Association convenes the largest meeting of Alzheimer’s scientists every year – the Alzheimer’s Association International Conference

(AAIC). This year in Boston, over 5,000 scientists attended AAIC to share research results, compare progress, and develop new working collaborations to advance the fight against the disease.

The third pillar of our program is the sharing of information. We initiated the International Society to Advance Alzheimer's Research and Treatment (ISTAART), a professional society that encourages networking among Alzheimer's researchers so they can share their findings and learn from each other. We also publish *Alzheimer's & Dementia*, which has been rated as the highest impact dementia journal and the third in impact among 191 clinical neurology journals. *Alzheimer's & Dementia* provides a single peer-reviewed publication for the global scientific community to report the latest research developments and results.

The fourth and final pillar of our global research efforts is investing in large-scale projects to overcome common barriers in the field of Alzheimer's. Projects include TrialMatch™ -- an individualized clinical trial matching service for people with Alzheimer's and other dementias -- World Wide Alzheimer's Disease Neuroimaging Initiative (WW-ADNI) -- the umbrella organization of neuroimaging initiatives being conducted around the world -- and the Cerebrospinal Fluid (CSF) Quality Control Program -- which brings together laboratories across the globe with the aim of standardizing the measurement of potential Alzheimer's biomarkers.

Changing the Trajectory of Alzheimer's

As I mentioned, no single organization can surmount a challenge as great as Alzheimer's. And no matter how important and critical the Association's global efforts are, we will not be successful without a serious and sustained commitment from the federal government. In 2010, the bipartisan National Alzheimer's Project Act (NAPA) (P.L. 111-375) passed Congress unanimously, requiring the creation of an annually-updated strategic National Alzheimer's Plan to help those with the disease and their families today and to change the trajectory of the disease for the future. The Plan is required to include an evaluation of all federally-funded efforts in Alzheimer's research, care, and services -- along with their outcomes. NAPA will allow Congress to assess whether the nation is meeting the challenges of this disease for families, communities, and the economy. Through its annual review process, NAPA will, for the first time, enable Congress and the American people to answer this simple question: are we making satisfactory progress in the fight against Alzheimer's?

As mandated by NAPA, the Secretary of Health and Human Services, in collaboration with the Advisory Council on Alzheimer's Research, Care, and Services, developed the first-ever *National Plan to Address Alzheimer's Disease* in May 2012, with an update released in June 2013. The Advisory Council, composed of both federal members and expert non-federal members, is an

integral part of the planning process as it advises the Secretary in developing and evaluating the annual Plan, makes recommendations to the Secretary and Congress, and assists in coordinating the work of federal agencies involved in Alzheimer's research, care, and services.

Having a Plan with measurable outcomes is important. But unless there are resources to implement the Plan and the will to follow through on its action steps, we cannot hope to make much progress. If we are going to succeed in the fight against Alzheimer's, Congress must provide the resources the scientists need. A disease-modifying or preventive therapy would not only save millions of lives but would save billions of dollars in health care costs. According to an economic model developed by the non-partisan health econometrics firm, The Lewin Group, a treatment that delayed the onset of Alzheimer's by five years (a treatment similar to anti-cholesterol drugs) would reduce Medicare and Medicaid spending on people with Alzheimer's nearly in half in 2050.

Because of the Plan, the National Institutes of Health (NIH) finally has created a blueprint for Alzheimer's research that includes a timeline and milestones toward the goal of preventing and effectively treating Alzheimer's by 2025. And, we are grateful for the additional resources that NIH has provided for Alzheimer's research in the past couple of years, including the recent announcement by NIH Director Francis Collins that \$45 million in additional funding would go to Alzheimer's research. These are, however, baby steps. According to a study published earlier this year in the *New England Journal of Medicine*, dementia is the most expensive disease in America. We do not have a commitment on research funding commensurate with this crisis. For every \$27,000 that Medicare and Medicaid spend caring for individuals with Alzheimer's, NIH spends only \$100 on Alzheimer's research. Scientists fundamentally believe that we have the ideas, the technology, and the will to develop new Alzheimer's interventions. But progress depends on a prioritized scientific agenda backed up by the necessary resources to carry it out.

The scientists have determined that additional research on Alzheimer's is a priority, and they have asked Congress to provide an additional \$80 million in funding for fiscal year 2014. Their budget request reflects the urgent need for Alzheimer's research and the scientific opportunity that now exists. It is vital that Congress support the research projects the scientists at NIH deem necessary.

What Needs to Be Done at the G8 Meeting

But just as the Alzheimer's Association cannot go it alone, so, too, the United States cannot go it alone. Congress recognized this when it passed NAPA, which requires the Secretary of Health and Human Services to coordinate with international bodies "to integrate and inform the fight against Alzheimer's globally." In 2012, the World Health Organization called dementia a public health

priority, and now dementia research must become a global priority. The G8 Summit in London on December 11 is a unique opportunity for international leaders to tackle dementia on a global scale, and it presents a historic opportunity to transform our commitment and approach.

The Alzheimer's Association believes that if the G8 is going to make a difference in dementia policy and research, then the G8 nations must develop a collaborative, global action plan for government, industry, and nonprofit organizations to work collaboratively and effectively on an international scale, with appropriate infrastructure and policies in place that break down barriers to effective research.

Specifically, it is vital that the G8 nations develop a shared vision for driving dementia research over the next decade to ensure the development of effective treatments for people worldwide. This vision should include a commitment by each country to increase its own funding into the cause, cure, and prevention of dementia to a level proportionate to the human and economic burden of the disease. It must include identifying additional, innovative funding models, such as public-private partnerships. It must involve improved coordination in research efforts among governments, the research community, non-profit organizations, and industry. And, it must include a commitment to creating a research environment that attracts, develops, and trains the very best scientists, clinicians, and health care professionals.

Finally, each G8 country must commit to having a national Alzheimer's and dementia plan of its own, just as the United States, the United Kingdom, and France have – plans that evaluate progress and share results to determine the best practices and most effective policies.

Moving Beyond the G8 Summit

But, let's be clear: the G8 summit is not the end of the process; it is only the beginning. As important as it is for the G8 countries to develop a shared vision, a shared commitment, and a shared strategy for moving forward, it is equally important that there be concerted and sustained action following the Summit. The vision, the commitment, and the strategy must be implemented if we are to succeed.

The G8 Summit must also be just the start of a wider global conversation about making dementia a global priority. Other global bodies, including the World Health Organization through efforts such as the Global Action Plan on the Prevention and Control of Noncommunicable Diseases, must work to support not only increased dementia research but also the development of care and support

systems in low- and moderate-income countries to relieve the dramatically growing impact of dementia on their health and social systems.

Mr. Chairman, medical research has transformed the lives of millions living with heart disease, stroke, HIV/AIDS, and cancer. Now is the time to make dementia a priority.

Thank you again for inviting me to participate in this important discussion about the global impact of Alzheimer's disease and the G8 Summit on dementia research. The Alzheimer's Association commends the Subcommittee for holding today's hearing, and we look forward to continuing to work with you to do all we can to improve the lives of those living with Alzheimer's as well as of those who care for them.