



U.S. House Foreign Affairs Committee  
Subcommittee on Africa, Global Health, Global Human Right, and International Organizations  
A Report on the G8 Dementia Summit

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Good afternoon Chairman Smith, Ranking Member Bass and members of the Subcommittee. Thank you for the opportunity to testify on the recent G8 Dementia Summit. We really appreciate your commitment to this issue -- both with the hearing prior to the Summit and this follow-up hearing.

Dementia is a condition fast becoming one of the world's largest and most expensive health issues. It is affecting lives and decimating health and social care systems across the world. Thirty-six million people worldwide have dementia and this number will double within a generation. As was stressed during the G8 Dementia Summit in London on December 11, 2013, research must be a global priority if we are to improve care, find preventions and treatments, and ultimately cure dementia. The Summit was a historic opportunity for international leaders to tackle dementia on a global scale. However, it will take concerted and sustained action from world leaders to tackle one of the world's largest and most expensive health issues.

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 part of every major research advancement over the past 30 years. Likewise, the Association works to enhance care and provide support for all those affected by Alzheimer's and reaches millions of people affected by Alzheimer's and their caregivers.

### **The Global Impact of Alzheimer's**

Alzheimer's disease is a global crisis. This crisis is placing – and will increasingly place – an enormous strain on the health care system, families, 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 on this planet.

In 2010, Alzheimer's Disease International (ADI) released the *World Alzheimer Report 2010: The Global Economic Impact of Dementia*, which explores the cost of dementia to our societies. ADI is the international federation of Alzheimer's associations around the world; the Alzheimer's Association is the sole United States member of ADI.

According to ADI's 2010 Report, the global cost of dementia consumes one percent of global Gross Domestic Product (GDP) and currently costs the world \$604 billion, with 70 percent of the costs incurred by North America and Western

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Europe. If dementia were a country, it would be the 18th largest economy globally. As we all live longer, dementia is spiraling out of control, holding healthcare systems ransom. This cost trajectory can only be fundamentally altered through prevention and effective treatments.

Research shows that most people currently living with dementia have not received a formal diagnosis. In the United States, as many as a half of the over 5 million individuals with Alzheimer's have not been diagnosed, while a study of India found nearly 90 percent remain unidentified. These studies suggest that nearly 28 million of the 36 million living with dementia have not been diagnosed and therefore do not have access to treatment, care and organized support that getting a formal diagnosis can provide.

The need for research was also underscored this year when ADI launched the 2013 World Alzheimer's Report. This year's World Alzheimer's Report theme focused on long-term care. The report, "Journey of Caring," emphasizes that care associated with Alzheimer's disease and other forms of dementia is a global issue that must be addressed as prevalence and costs continue to soar, placing enormous stress on families and nations alike.

As the world 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.

The report recommends that governments around the world should make dementia a priority by implementing national plans, much like the *National Plan to Address Alzheimer's Disease*, and by initiating urgent national debates on future arrangements for long-term care. It goes further by stating that systems should be in place to monitor the quality of dementia care in all settings, while promoting autonomy and choice at all stages. These are all priorities that can strengthen the state of long-term care, and keep individuals with Alzheimer's in the best possible settings for care.

### **Alzheimer's Association Global Research Efforts**

The Alzheimer's Association is committed to accelerating the global effort 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 in the global race to end Alzheimer's. We believe in the value of collaboration and work toward the day when we will have disease-modifying treatments, preventive strategies and gold-standard care for all people affected by Alzheimer's disease.

The Association formula for progress in research rests on four pillars: Funding, increasing collaborations 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 expended outside the US. Currently, we fund active grants in 21 countries, and have funded research in 28 overall. We fund across the total spectrum of Alzheimer's research from molecular biology to medical systems investigation. Our funding is peer-reviewed by a vast international network of volunteer scientists and quality-assured by our Medical and Scientific Advisory Council, a group of distinguished professionals who represent a range of dementia research, including bench research, clinical care, community health and support services. In addition to funding research directly, we work to ensure the federal investment in Alzheimer's research is comparable with the public threat of the disease.

The second pillar of the Alzheimer's Association program is encouraging increased cooperation between scientists. The Association is responsible for the largest meeting of Alzheimer's scientists every year. This year, the Alzheimer's Association International Conference (AAIC), attracted over 5,000 scientists to Boston to compare, reveal progress, and develop new collaborations to advance research. AAIC provides a platform for presentation and discussion of all aspects of Alzheimer's research from genetics to animal models, pathology, biomarkers, interventions, and social and behavioral issues. By encouraging the attendance of researchers from around the world, the Alzheimer's Association is able to bring new innovations in Alzheimer's research to a single thought forum designed to accelerate the understanding of Alzheimer's and related dementias. Also within this pillar is the Association's International Society to Advance Alzheimer's Research and Treatment (ISTAART), an international scientific society to bring researchers together to work on understanding the causes of and potential treatments for Alzheimer's and other dementias.

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The third pillar of our program is sharing of information. We publish *Alzheimer's & Dementia*, the official journal of the Alzheimer's Association. This journal allows important progress to be collected in one place to increase efficiency of Alzheimer's research. For example, the criteria defining Alzheimer's disease was published in *Alzheimer's & Dementia*. We partnered closely with the National Institute on Aging (NIA) of the National Institutes of Health to develop the first new criteria and guidelines in 30 years to diagnose Alzheimer's disease. In addition, a report, which reflected the collective views and recommendations of leaders in Alzheimer's disease research, outlined a goal-directed scientific agenda to aid in the implementation of the National Alzheimer's Project Act (NAPA)'s National Plan.

The fourth and final pillar of our program is selectively investing in projects to overcome common barriers in the field of Alzheimer's. Projects included in this effort include TrialMatch™, World Wide Alzheimer's Disease Neuroimaging Initiative (WW-ADNI), the Cerebrospinal Fluid (CSF) Quality Control Program, the Hippocampal Harmonization Project, Alzheimer's Association Research Roundtable, the Accelerating Medicines Partnership and the Global Alzheimer's Association Interactive Network (GAAIN).

### **TrialMatch™**

TrialMatch™ is a confidential, free, and interactive tool that provides comprehensive clinical trial information and an individualized trial matching service for people with Alzheimer's disease and related dementias. Recruiting and retaining trial participants is now the greatest obstacle, other than funding, to developing the next generation of Alzheimer's treatments.

### **World Wide Alzheimer's Disease Neuroimaging Initiative (WW-ADNI)**

WW-ADNI, which the Alzheimer's Association is the administrative home of, is a collaborative effort of scientists from around the world and is the umbrella organization for neuroimaging initiatives being carried out through the North American ADNI, European ADNI (E-ADNI), Japanese ADNI, Australian ADNI (AIBL), Taiwan ADNI and two new initiatives in Brazil and India. The Initiative unites leading international Alzheimer's investigators in a common effort to:

- Help predict and monitor the onset and progression of Alzheimer's disease
- Globally harmonize neuroimaging and other biomarker collection, analysis and interpretation
- Document cognitive changes linked to physical changes
- Share data across the international research community.

Ultimately, we aim to better understand the physical changes that occur in healthy individuals compared with asymptomatic individuals, those with mild cognitive impairment (MCI) and Alzheimer's disease. WW-ADNI focuses both on changes in the brain that can be identified with tools such as positron emission tomography (PET) and magnetic resonance imaging (MRI) and changes in fluids such as blood and cerebrospinal fluid (CSF). As its name suggests, another area of focus is to involve individuals from multiple sites around the world and to follow their progress over several years to gain a worldwide picture of the physical changes that lead to Alzheimer's disease.

Data from WW-ADNI are expected to play a key role in identifying effective treatments for Alzheimer's, as well as methods that may prevent the disease or slow its progression. Each WW-ADNI site collects participant data from MRI and PET scans. Other data on physical changes related to the onset and progression of MCI and Alzheimer's (called biomarkers) are also gathered. WW-ADNI is unique in that most of the clinical, neuropsychological, imaging, and biological data gathered is quickly made available to the scientific community worldwide at no cost, allowing researchers to use the information when designing or evaluating their own research.

### **International Alzheimer's Disease Research Portfolio (IADRP)**

This joint collaboration between the National Institute on Aging (NIA) and the Alzheimer's Association develops a database and tools for assessing the research portfolios of international funding organizations for areas of overlap or gaps, as well as areas of opportunities in which to collaborate. Currently, 13 international funding organizations, representing 27 countries, have submitted funding profiles and grants. This database and associated tools will help to support strategic planning and can help to leverage critical resources between international organizations.

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### **Alzheimer's Association International Efforts to Harmonize the Development of Alzheimer's Biomarkers**

The Alzheimer's Association 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. Several studies, including studies involving data from the ADNI, have shown that levels of biomarkers in CSF are often accurate predictors of which individuals will go on to develop Alzheimer's disease. CSF biomarkers may be useful not only in aiding early detection of Alzheimer's and improving diagnostic accuracy, but also in identifying and monitoring the effects of drugs in clinical trials, understanding the molecular changes that lead to Alzheimer's, and helping to ensure that individuals recruited into Alzheimer's clinical trials are on a path toward developing the disease.

### **Alzheimer's Association Research Roundtable (AARR)**

The AARR is a consortium of scientists from the pharmaceutical, biotechnology, diagnostics, imaging and cognitive testing industries, and senior staff and advisors from the Association. AARR members seek to facilitate the development and implementation of new treatments for Alzheimer's disease by collectively addressing obstacles to research and development, clinical care and public health education. Begun in 2003 with four sponsors, the Research Roundtable now includes more than 26 corporate sponsors that sponsor worldwide research and clinical trials. Each company sends several senior scientists to the Roundtable to benefit from the state-of-the-field scientific presentations, collegial interactions and networking opportunities. To help address these obstacles, the dialogue and presentations also include investigators from academia and government organizations such as the U.S. Food and Drug Administration (FDA); its European equivalent, the European Medicines Agency; and the National Institutes of Health (NIH).

### **Accelerating Medicines Partnership**

The Alzheimer's Association is also proud to be a founding Steering Committee Member of the newly formed Accelerating Medicines Partnership (AMP), formerly the Target Validation Consortium, which is a pre-competitive collaboration among government, academia and industry, convened to harness collective capabilities and scale resources toward improving current efforts to develop new therapies for complex, heterogeneous diseases. The focus of the partnership is doing the research necessary to understand these diseases more fully and identifying the right targets to pursue for drug therapy, thereby accelerating the ability to bring new medicines to patients with these diseases.

### **The Global Alzheimer's Association Interactive Network (GAAIN)**

Tying all of these efforts and global efforts overall in the Alzheimer's ecosystem, is a new program launched by the Alzheimer's Association, the Global Alzheimer's Association Interactive Network (GAAIN). GAAIN is a project that provides Alzheimer's disease scientists worldwide, freely available access to a vast amount of federated neuroscience data. GAAIN will change the way researchers work together to answer questions related to the causes, diagnosis, treatment and prevention of Alzheimer's and other neurodegenerative diseases. Built on an international database framework already in use by thousands of scientists in North America and Europe, GAAIN makes data available for searching, downloading and analyzing across a shared network accessible from anywhere via the Internet. Alzheimer's scientists can retrieve the most current information from the world's foremost laboratories. GAAIN will allow researchers to extract specific material relevant to their own investigations, helping them arrive at more reliable and precise conclusions to speed our understanding of Alzheimer's disease and advance the discovery of new treatments, preventions and cures.

### **Changing the Trajectory of Alzheimer's**

Until recently, there was no federal government strategy to address this looming crisis. In 2010, thanks to bipartisan support in Congress, the National Alzheimer's Project Act (NAPA) (P.L. 111-375) passed unanimously, requiring the creation of an annually-updated strategic National Alzheimer's Plan (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: *Did we make satisfactory progress this past year in the fight against Alzheimer's?*

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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 of 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.

In addition to improving health outcomes for people living with Alzheimer's and for reducing the financial impact of Alzheimer's on families and our Federally funded programs, NAPA requires the Secretary of Health and Human Services to coordinate with international bodies to integrate and inform the fight against Alzheimer's globally. We hope that the Secretary will continue to work with her global partners to improve the treatment and care of the millions of people living with Alzheimer's.

Having this Plan with measurable outcomes is important. But unless there are resources to implement the Plan and the will to abide by it, 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. Specifically, 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 nearly in half in 2050.

Today, despite the federal investment in Alzheimer's research, we are only just beginning to understand what causes the disease. Americans are growing increasingly concerned that we still lack effective treatments that will slow, stop, or cure the disease, and that the pace of progress in developing breakthrough discoveries is much too slow to significantly impact this growing crisis. For every \$27,000 Medicare and Medicaid spend caring for individuals with Alzheimer's, the National Institutes of Health (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 that progress depends on a prioritized scientific agenda and on the resources necessary to carry out the scientific strategy for both discovery and translation for therapeutic development.

There is additional funding in the NIH budget because the scientists have determined that additional research on Alzheimer's is a priority. Their budget request reflects the changing needs of the Alzheimer's community and the scientific opportunity. It is vital that Congress support the research projects the scientists at NIH deem necessary.

### **The G8 Meeting: Collective Planning, Collective Goals**

The first-ever G8 Dementia Summit was an unprecedented opportunity to advance progress internationally, to make Alzheimer's and dementia research a global priority and to promote increased global collaboration. The Summit also underscored the need for all nations to collectively confront the human and economic costs of dementia, and take advantage of the scientific opportunities that hold promise for better diagnosis, treatment and prevention.

As a presenter at the Summit, I outlined the most important steps to improve the lives of those with dementia - direct care and support, research investment and collaboration - all items that the Alzheimer's Association and our counterparts in the other G8 nations are actively engaging in. Additionally, there is great promise with GAAIN which will allow researchers worldwide to accelerate their efforts by sharing information.

The Alzheimer's Association is on the front lines of this epidemic, but it is clear that we alone cannot overcome it. Governments and industry must also be actively engaged and all of those affected must raise their voices.

The G8 Summit concluded with the publication of a declaration and communique setting out the agreements reached, many of which are core tenets of the *National Plan to Address Alzheimer's Disease*. The countries agreed to:

- Commit to identify a cure, or a disease-modifying therapy, for dementia by 2025;
- Significantly increase the amount spent on dementia research;
- Increase the number of people involved in clinical trials and studies on dementia;

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- Establish a new global envoy for dementia innovation, following in the footsteps of global envoys on HIV and AIDS and on Climate Change;
- Develop an international plan for research;
- Share information and data from dementia research studies across the G8 countries to work together and get the best return on investment in research; and
- Encourage open access to all publicly-funded dementia research to make data and results available for further research as quickly as possible.

### **Moving Forward**

The G8 Dementia Summit was not the end; it was the beginning. 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. Working together, governments, the research community, non-profit organizations and industry need to make plans made at the Summit a reality. The Alzheimer's Association is pleased that the G8 countries have shown a commitment to increased investment and improved coordination in research that will transform the lives of people with dementia across the globe.

It will take concerted and sustained action from world leaders to tackle dementia. The declaration and communique is just the first step in advancing dementia research, and to taking collaborative global action that will meaningfully impact the lives of those affected by dementia. The Summit was the start of a process aimed at putting dementia at the top of the global health agenda and the top of the agendas of health leaders from around the world. Additional international meetings will be held in the coming year to ensure that Alzheimer's is and remains a global priority. In addition to our upcoming Alzheimer's Association International Conference (AAIC) which will be held in Copenhagen, Denmark, in July 2014 and Washington, D.C. in July 2015, meetings will be hosted by the UK and Japan; Canada and France will hold a joint meeting; and Dr. Francis Collins announced a meeting to be held in February 2015 to examine the progress of the G8 Alzheimer's research effort.

Thank you again for inviting me to participate in this important discussion about the global impact of Alzheimer's disease. The Alzheimer's Association commends the Subcommittee for today's hearing and looks forward to continued work together to do all we can to improve the lives of those contending with Alzheimer's, as well as for those who care for them.