

The Global Challenge of Alzheimer's Disease
Congressional Hearing of the Subcommittee on Africa, Global
Health, Global Human Rights and International Organizations
Chairman Chris Smith
November 29, 2017

As we open today's hearing, there are an estimated 47 million people in the world living with Alzheimer's disease and other forms of dementia—more than the entire population of Spain—according to a report by Alzheimer's Disease International.

And according to Dr. Marie Bernard, Deputy Director of the National Institute on Aging who we will hear from today, this number is estimated to grow to 115 million by 2050 as populations around the world age. The total estimated global cost of addressing this condition today is \$818 billion, but by as early as next year, it is estimated that this cost will rise to at least one trillion dollars.

Alzheimer's is a cruel disease, robbing its victims of their memories and their very identities, and robbing their family and friends of the person they know and love. It is excruciatingly painful for someone to lose themselves gradually. But what of those who love them? Death can rob you of a loved one suddenly, but Alzheimer's gradually takes them from you before your very eyes. There are isolated points at which they may be back to themselves momentarily, only to fade away once more.

In 1999, I co-founded the Congressional Task Force on Alzheimer's Disease, which I still co-chair today, to bring this disease to the forefront of

the congressional agenda, advance support for federal research, and increase awareness. The Task Force worked in partnership with the Alzheimer's Association to unanimously pass the National Alzheimer's Project Act (PL 111-375) which established an Advisory Committee of private and federal experts to work with the Secretary of Health and Human Services to comprehensively assess and address Alzheimer's research, institutional services and home and community-based care, with a goal to identify a cure or disease-modifying therapy for dementia by 2025. Today, there are over 170 Members in the House and Senate.

This year, I worked with my Task Force Co-Chair, Representative Maxine Waters, to request an increase of \$414 million to the Alzheimer's Research Funding at NIH. Under HHS Appropriations Chairman Tom Cole's extraordinary leadership, the Fiscal Year 2018 omnibus appropriations bill, passed on September 14, 2017 included a \$400 million increase for Alzheimer's disease research at NIH. This would bring total funding to \$1.814 billion. Currently funded at \$1.4 billion, NIH spending on Alzheimer's research has almost tripled since Fiscal Year 2015, when \$589 million was allocated for research.

The majority of people with Alzheimer's or other forms of dementia have not received a diagnosis so they are unable to access the care and treatment they so desperately need. This is true in the developed world, but it is even truer in the developing world. Michael Splaine points out in his testimony that detection and diagnosis are a stubborn problem everywhere. Research shows that most people currently living with dementia have not

received a formal diagnosis. In high income countries, on 20-50% of dementia cases are recognized and documented in primary care. This ‘treatment gap’ is certainly much greater in low and middle income countries. Without a diagnosis, there can’t be treatment, care and organized support or opportunity to volunteer for clinical research.

Of course, even when Alzheimer’s or other forms of dementia are diagnosed, care is too often fragmented, uncoordinated and unresponsive to the needs of people living with this condition. In response, last Congress I introduced the “Health Outcomes, Planning, and Education (HOPE) for Alzheimer’s Act” of 2015 to provide Medicare coverage for a care planning session for patients newly-diagnosed with Alzheimer’s disease, family caregivers or legal representatives. In recognition of this great unmet need, this legislation garnered 310 bipartisan cosponsors. Ultimately, Medicare adopted an amended version of the HOPE benefit in the final rule for Calendar Year 2017 Physician Fee Schedule.

Of course, Alzheimer’s robs its victims not only of their memories and awareness, but also their lives. In the *American Journal of Public Health Research* survey of years of life lost versus number of deaths between 1995 and 2015, annual deaths due to Alzheimer’s complications in the United States alone rose from 20,607 in 1995 to 110,568 in 2015. During that period, Alzheimer’s rose from the 14th leading cause of death among ailments in this country in 1995 to number six in 2015.

This is the fourth hearing I have chaired on Alzheimer’s disease.

- On June 23, 2011 this Committee held a hearing on Global Strategies to Combat the Devastating Health and Economic Impacts of Alzheimer's Disease.
- On November 21, 2013 I chaired the Global Challenge of Alzheimer's: The G-8 Dementia Summit and Beyond.

In December 2013, the G8 nations adopted a goal to identify a cure or disease-modifying therapy for dementia by 2025, which corresponds to the US' National Alzheimer's Project Act. The G8 agreement resulted in the creation of the World Dementia Council as a vehicle to drive forward the G8 commitments. Despite this progress, the massive health and economic threat of Alzheimer's and dementia globally is growing.

- On January 15 2014, this Committee held a hearing to Report on the G8 Dementia Summit.

Today's hearing is intended to examine the existing and potential options for prevention and treatment of this often devastating disease, and the harrowing statistics cited earlier likely would be much worse in developing countries if they had accurate identification of Alzheimer's and records of victims and deaths.

As our hearing testimony will demonstrate, there is hope for Alzheimer's patients, their families and friends. For example, a research team from the Columbia University Medical Center in 2013 said they had finally traced Alzheimer's to its earliest developmental stages—a discovery that they believed could lead to more-effective treatments. In *Science*

Translational Medicine two years ago, Australian researchers explained a non-invasive ultrasound technology that clears the brain of neurotoxic amyloid plaques - structures that are responsible for memory loss and a decline in cognitive function in Alzheimer's patients. By 2016, scientists at the Institute for Regenerative Medicine at the University of Zurich said they were amazed to find that patients treated with the highest dose of the antibody drug aducanumab (ah-doo-can-oo-mab) experienced an almost complete clearance of the amyloid plaques that prevent brain cells communicating, leading to irreversible memory loss and cognitive decline.

Our witnesses today will tell us more about these and other advances that offer hope that Alzheimer's – if not effectively prevented – can at least be more successfully treated. Once we in developed countries can get a better handle on diagnosing and treating Alzheimer's, we hope to share what we know with developing countries so their citizens can better escape what has in the past been a very bleak future for all concerned.

While we work to prevent and find a cure for Alzheimer's, we must not neglect those currently living with this disease and address the public health crisis we are currently facing. This Congress, I joined my colleagues in introducing the “Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act”. This bill establishes Alzheimer's Centers of Excellence around the country, provides funding to state and local health departments to implement interventions and best practices from the Centers of Excellence; and increases the collection, analysis, and reporting of data on cognitive decline and caregiving to inform future public health actions.

Additionally, I have re-introduced Kevin and Avonte's Law to reauthorize and expand the Missing Alzheimer's Disease Patient Alert Program to address the issue of wandering among individuals with Alzheimer's and children with disabilities. It's common for a person with Alzheimer's to wander and/or become lost, and it can happen at any stage of the disease. 6 in 10 individuals with Alzheimer's will wander at some point. They may try to go home when already there or attempt to recreate a familiar routine, such as going to school or work. Funding from this program could be used to provide proactive educational programming to prevent wandering to families & caretakers of individuals who wander, as well as training to first responders in order to recognize and respond to endangered missing individuals and facilitate their rescue and recovery. This funding could also be used for innovative locative technology for law enforcement that would facilitate rescue and recovery.

Next week, I will re-introduce the Global Brain Health Act to increase research on prevention and treatment of autism, hydrocephalus, Alzheimer's and other forms of dementia. This legislation would encourage the building of treatment capacity for these brain disorders among caregivers in developing countries and support increased international cooperation in research and implementation of strategies on prevention and treatment. These actions also would benefit those with these disorders here in the United States.