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Before the House Subcommittee on Africa, Global Health, **Global Human Rights and International Organizations**

A Report on the G8 Dementia Summit Wednesday, January 15, 2014

Chairman Smith, Ranking Member Bass and other members of the Committee. Thank you for convening this important follow-up hearing to the session you held two months ago just prior to the landmark G8 Dementia Summit. I applaud you for your prompt follow-up and thank you for inviting me to testify a second time.

I am testifying today as the Convener of the Global CEO Initiative on Alzheimer's, a coalition of 12 major global companies – including firms in the medical diagnostics, biopharmaceuticals, financial services, medical foods, and home health care sectors – that is committed to partnering with government to achieve the goal of preventing and effectively treating this disease by 2025. Our members include GE, Lilly, Sanofi, Pfizer, Takeda, Bank of America, Nestle Health Science, Merck, and Home Instead among others. In addition to convening – along with the NIH and the New York Academy of Sciences – the Path to 2025 Summit in November, we were also engaged for much of last year with the British government in the planning of December's G8 Dementia Summit hosted by Prime Minister Cameron, at which the G8 nations committed to the 2025 goal; to "collectively and significantly" increase public investment in the research needed to achieve that goal; and to advance innovations in the delivery of care for families touched by dementia, of which Alzheimer's is the most prominent cause.¹

Much has occurred between your November hearing and today. You just heard a very comprehensive report from Dr. Hodes on our government's participation in the Summit and the plans for substantive follow-up activity over the coming months through a series of workshops

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and a planned February 2015 follow-up Summit hosted here in Washington. The CEOi convened senior leaders in business, science and government on December 12, the day following the G8 Summit, and set in place an action-oriented agenda for 2014. We will be working with the G8 governments to follow up on that agenda this year.

Fifteen years ago, it was U.S. leadership that helped mobilize the global community to combat HIV/AIDS. The G8's embrace of a goal to develop a cure or disease-modifying therapy for dementia by 2025 – a slight variation to our own bold and time-based goal set two years ago – demonstrates that U.S. leadership is once again becoming critical to another global effort, this time against Alzheimer's (a term I will use as including all forms of dementia).

As we discussed in November, the parallels between the scale of the Global HIV/AIDS and Global Alzheimer's challenges are striking. Shortly after the November hearing, Alzheimer's Disease International released an updated estimate that more than 44 million people worldwide are living with dementia today. This figure represents a 22 percent increase from the previous estimate of 36 million people issued just three years earlier. This change was driven largely by new estimates for China and Sub-Saharan Africa. If this trajectory remains unchanged, the report estimates we will have more than 75 million cases of dementia worldwide by 2030 and more than 135 million cases by the mid-century point. To put these figures in context, today's 44 million people with dementia is larger than the populations of Canada, Poland, or Argentina, and the 135 million people projected by 2050 would exceed the population of Japan and nearly reach that of Russia, the tenth and eleventh most populous nations on earth.²

Perhaps even more concerning than the top-line number is that more than 62 percent of persons with dementia live in low-to-middle income countries, a statistic that will exceed 70 percent come 2050 based on the current trajectory. Think, for a moment, of what this means. Most of us know and have personally experienced the immense challenges in caring for a

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² See: https://www.cia.gov/library/publications/the-world-factbook/rankorder/2119rank.html

patient with Alzheimer's disease here in the United States, one of the richest nations in the world. Now think about how much more arduous – for the patient, his or her family caregivers, and society as a whole – this task becomes when done in the developing world? Think about how this caregiving burden will set back the gains against abject poverty that have been made in many countries in recent years, particularly gains made by women who often bear disproportionate burdens as caregivers.

At the last hearing, we discussed the many parallels that exist between the response to the global HIV/AIDS challenge and the need for a similar response to the global Alzheimer's challenge. Around the dawn of this millennium, the number of global HIV/AIDS cases were thought to be between 30 to 36 million compared to an estimated 44 million Alzheimer's cases today.^{3 4} The HIV/AIDS epidemic spurred leaders in the United States and the world to respond with the Global Fund to Treat AIDS, Tuberculosis and Malaria, as well as the President's Emergency Plan for AIDS Relief or PEPFAR. Often overlooked, however, is Congress's leadership in driving both of these programs. In the summer of 2000, Congress passed and then President Clinton signed into law the Global AIDS and Tuberculosis Relief Act. This law authorized an aggressive U.S. response to the global HIV/AIDS crisis and established the World Bank AIDS Trust Fund, among other things.⁵

The global actions led by the US and G8 against HIV/AIDS, including the Global Fund and PEPFAR, were and continue to be stunningly successful by most measures, particularly when it comes to preventing new cases of HIV and reducing the number of AIDS deaths. With regard to new cases of HIV/AIDS, we have experienced a 33 percent decline from 2001 to 2012. Deaths from AIDS have also dropped sharply, going from an estimated 2.3 million in 2005 to 1.6 million in 2012. With such amazing success, it is easy to forget the dire predictions of the ravages of HIV/AIDS made a little more than a decade ago. In November 2000, the United Nations issued a

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³ http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5021a3.htm#fig1

⁴ http://www.unaids.org/en/dataanalysis/datatools/aidsinfo/

⁵ https://www.govtrack.us/congress/bills/106/hr3519/text

⁶http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_201 3 en.pdf

release saying the more than 36 million people living with HIV/AIDS was more than 50 percent higher than the population that had been predicted in 1991.

Imagine for a moment the headlines we would be reading today had the world not responded as it did to Global HIV/AIDS. What would the face of HIV/AIDS look like today? How many tens of millions of people – at home and abroad – would be suffering, their disease going untreated? How many new cases and deaths would be reported each year? What would have been the impact on economic development? How many orphans, children who would be extremely vulnerable to the many threats of exploitation, such as human trafficking, would we see each year? Thankfully, the U.S., other nations, industry and the philanthropic community did act in time. And the result?

- More than \$30 billion has been pledged to the Global Fund alone to deliver treatments and means of prevention to people throughout the world, with 6 million people receiving antiretroviral therapies alone;⁷
- The pharmaceutical industry dropped the prices for treatments to increase access;
- Seven of the 10 fastest growing nations in the world are now in sub-Saharan Africa⁸; and
- We are now able to celebrate declines in new cases and the death rate.

Even today, the global HIV/AIDS stakeholders are addressing the improvements that are still needed to eradicate this devastating disease, including improved distribution of and access to treatments, and the development of vaccines.

What Did We Learn from the HIV/AIDS Experience?

Nations are Zimbabwe, South Sudan, Uganda, Niger, Burundi, Burkina Faso, and Mali.

⁷ See: http://www.theglobalfund.org/en/infographics/2013-11-27 Results at End 2013/

⁸ See: https://www.cia.gov/library/publications/the-world-factbook/rankorder/2002rank.html

Professor Peter Piot, the former head of UNAIDS and the person responsible for turning HIV/AIDS from a global epidemic into a manageable disease, calls Alzheimer's the next great epidemic and a public health "time bomb." Noting that epidemics do not respect national boundaries, he urges a global response in the form of a coordinated global action. And it is clear that we must plan for how we will detect, diagnose, and treat populations in nations as diverse as the US, China, and Italy. This means low-cost diagnostics and therapies; it means vaccines where infrequent administration will overcome difficulties of cost, access, and administration; and it means modes of care delivery designed with ease-of-planning and adaptability to different cultural and health system environments.

While there are many similarities between HIV/AIDS and Alzheimer's, there are also some key differences. Perhaps first and foremost, when the global community decided to address HIV/AIDS, the means of treating HIV were well-known, and disease-modifying and life-saving treatments had been developed. The challenge was one of affordability, access and administration. Unfortunately, Alzheimer's lacks both a means of prevention and a disease-modifying therapy, which of course are the objective of the U.S. – and now the G8 – 2025 goal. Despite this difference, a comprehensive, robust, and coordinated Global Plan to Stop Alzheimer's and a corresponding Global Alzheimer's Fund are urgently needed. A growing chorus of leaders, including Prof. Piot and leaders of the G8, have recognized the need for global planning, coordination and funding, and we must move forward to make this a reality right now.

The Time is Now to Address the Global Alzheimer's Crisis

The time has come for the United States to once again lead the global community against the grave threat to our health and finances, the threat posed by Alzheimer's and dementia. What will the future look like if the world turns a blind eye to this crisis? We are on the verge of a humanitarian crisis that is larger than the threat posed by HIV/AIDS. Beyond the public health

challenge, we are also on the front edge of an economic and fiscal crisis. The costs of Alzheimer's to health care and social support systems is huge and growing, already at more than 1 percent of global GDP. And Alzheimer's is a significant driver of the growth in entitlement spending in the developed and developing world resulting from the rapid change in aging demographics.

In its 2010 report entitled Global Aging: An Irreversible Truth, Standard & Poors identified global aging "the dominant threat to global economic stability – without sweeping changes to age-related public spending, sovereign debt will soon become unsustainable." In their 2013 update, S&P noted that global aging "will lead to profound changes in economic growth for countries around the world – compounded by heightened budget pressures from greater age-related spending." S&P noted further that increases in health care spending "will likely be the biggest driver of higher-age spending in coming decades." They also predict increased costs associated with long-term care services for this growing population. Combined, these projections will place incredible strain on the fiscal well-being of the world's nations, including the United States. When you overlay the specter of nearly 140 million persons with dementia by mid-century, the need for coordinated and robust global action for a range of health, economic and fiscal reasons is apparent.

A Global Action Plan to Stop Alzheimer's & Dementia

I urge Congress to begin by laying a foundation for a Global Action Plan and corresponding fund, just as you did nearly 15 years ago for HIV/AIDS. Just as our National Plan to Address Alzheimer's focuses on research, care, services and support for caregivers, so too can a global strategic plan. It should be informed by existing national plans like our own and seek to leverage scarce resources by pooling resources and coordinating efforts against the highest priorities needs. A global action plan should also set international norms for research, care, and

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 $https://www.globalcreditportal.com/ratingsdirect/renderArticle.do?articleId=1098626\&SctArtId=145185\&from=CM\&nsl_code=LIME$

long-term supports and services so nations can learn from one another about what is expected, what is possible, and what mechanisms can be adapted for implementation in their countries. As a first step, we should expect that every country should develop a national Alzheimer's/Dementia plan. Beyond that basic foundation, we can, as the UK has done, set a norm for the percentage of a nation's dementia population which has been diagnosed with the disease. For those diagnosed, we can benchmark the percentage who have a care plan and, for those with a plan, the percentage who are receiving effective care and improved outcomes. With regard to research, can we set a norm, as recently suggested by Dr. Ron Petersen, who chairs our nation's Advisory Council on Alzheimer's Research, Care and Services, that one percent of a nation's estimated cost of caring for those with Alzheimer's be dedicated to research, either within that country or to a global fund. By setting these quantified international norms, nations will develop a comprehensive global response and be able to hold themselves, and all of us, accountable for periodic improvement in national and global response mechanisms.

But there are other transnational efforts that can add momentum to a global response. For example, at the G8 Summit and related follow-on events, a clear consensus emerged from industry, academia, and government that reforms in the clinical trial process would be a major step forward to reducing the time, cost, and risk associated with developing disease-modifying Alzheimer's therapies. It takes far too long and costs too much money to recruit and enroll patients in trials, to assemble needed infrastructure anew with every new drug candidate, and to conduct the trials only to see the hand crafted trial infrastructure dismantled. Recognizing this, the Global CEO Initiative has made addressing this gap a top priority for the year. Specifically, we will be working with other partners across multiple sectors to develop a Global Alzheimer's Clinical Trial Platform that creates sustainable, linked, and trial-ready global registries and cohorts of potential trial participants available to multiple companies and forms of clinical trials, thus avoiding the inefficiency and sluggishness of one-off trial infrastructures. A platform of this kind would be the type of groundbreaking initiative that could be supported via a global strategy and fund.

In addition, we are exploring innovative funding mechanisms that will attract increasing levels of private philanthropic, social, and financial capital to the Alzheimer's efforts. New forms of crowd-sourcing, hybrid philanthropic and financial venture investments, and social impact investing models are emerging in other fields and efforts are underway to assess their applicability to Alzheimer's. The boldest of these potential new models has been developed by Professor Andrew Lo of MIT. Building on conceptual work in the cancer field, he has posited the possibility of a large national or global fund of private capital where government either issues partial guarantees or credit enhancements justified by the potential of enormous public sector cost savings that would be produced by new disease-modifying therapies.

While these clinical trial and financing mechanisms are still in early development, they signal the willingness – indeed, the eagerness – of the private sector to work arm-in-arm with governments to address the global Alzheimer's epidemic. Just as the Bill and Melinda Gates Foundation has been critical to the success of the Global Fund, so too will philanthropic and similar commitments to the struggle against Alzheimer's.

In addition to taking these steps forward on the global front, I would submit that we must continue to lead by example by aggressively implementing our own National Plan and by increasing the level of our public resources to support Alzheimer's research and other programs. While government budgets remain constrained, as noted during the last hearing, taxpayers are already paying dearly for Alzheimer's, the to tune of about \$140 billion annually in Medicare and Medicaid costs attributable to the disease. At the same time, we spend about $1/3^{rd}$ of 1 percent of this amount on Alzheimer's research, about \$500 million annually. With that in mind, I urge Congress to take two actions with regard to research:

Double to \$1 billion in FY 15 the amount of money committed to Alzheimer's research;
and

• Set a marker, consistent with the international norm I recommend above, of committing just 1 percent of the total estimated costs of this disease to Alzheimer's biomedical research. With total public and private costs in the U.S. estimated to be about \$200 billion annually, this approach would yield a U.S. national goal of \$2 billion in annual research funding. This target matches the level of funding determined by leading Alzheimer's experts – and recommended by the Advisory Council – as the level of public funding necessary to achieve the 2025 goal.

Finally, I think it is worth revisiting a recommendation I and other members of the Advisory Council have long supported – a White House-level official tasked with coordinating our domestic and international efforts against Alzheimer's and dementia. At the G8 Summit, the United Kingdom committed to appointing a global Dementia Innovation Envoy to coordinate the nations' work in this space. While I am not a fan of layers of bureaucracy, I believe strongly in clear accountability. Congress should consider creating such a position to coordinate both domestic inter-agency efforts and our global leadership role against Alzheimer's.

Chairman Smith, I thank you, again, for convening this hearing and I urge this committee to continue your oversight and focus on this issue and to strongly consider reaching out to additional parliamentarians, particularly those in other G8 member nations, who share your strong interest in and commitment to forming a global working group of Parliamentarians against Alzheimer's. Such an alliance would support – indeed, drive – the work of government administrations in implementing the G8 commitments and expanding this effort. It is my hope that years from now, this committee can hold a hearing exploring the success story that was the U.S.-led global effort to stop Alzheimer's and look back to your series of hearings as seminal events toward achieving that goal.