Testimony of Ashley Campbell
Hearing on The National Plan to Address Alzheimer's Disease: Are We On Track to 2025?

Special Committee on Aging
United States Senate

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Mr. Chairman, Ranking Member Collins and members of the Committee, thank you for this opportunity to share with you how my family has been affected by Alzheimer's and the importance of the National Alzheimer's Plan. I would also like to thank the Special Committee on Aging for focusing on Alzheimer's, an escalating national epidemic. In my testimony today, I ask you to understand the human toll of this disease -- on my family and millions of others -- and I respectfully request that you support implementation of the National Alzheimer's Plan, including funding the President's FY 2014 budget request of an additional $100 million for Alzheimer's.

My family's story

Two years ago my father, Glen Campbell, announced that he had been diagnosed with Alzheimer's disease. This diagnosis came after years of short-term memory loss.

For my dad and my family, talking about his diagnosis publicly was important. It is important for people to know that individuals with Alzheimer's can keep doing what they love -- that life doesn't end right away when you are diagnosed with Alzheimer's. It was also important for my dad to help spread the word about the need for more research to find a cure for Alzheimer's.

For my dad, music has been therapeutic. If he can put that guitar in his hands and use his fingers to pick music, he's much better. And, he's comfortable on stage – sometimes more than if he's sitting at home or playing golf.

Shortly after my dad announced that he had Alzheimer's, my brothers and I joined my dad for the Glen Campbell Goodbye Tour. My mom was by Dad's side, of course, and we were also joined on tour by filmmakers who are doing a documentary about my dad.

For Dad, being public about his diagnosis was also helpful because he did not want people to get the wrong idea at concerts if something appeared to go awry. While there were a few challenges on stage during some of the shows, those were corrected and smoothed out quickly. His love to perform and play his music was always vibrant, even if at times the lyrics were tough to find or other elements on stage might momentarily frustrate him. It helped to have my brothers and me with him on stage, and it helped that my dad had been playing and touring for so long that the stage, for him, feels a lot like home.

As much as raising awareness of Alzheimer's was a driving force for my family, the response to the tour was phenomenal and heartwarming for all of us. People came out in droves and they totally supported my dad. My dad loved the crowds at the concerts — and they kept on loving him right back. From the first night of the tour until the last, I couldn't get over how supportive people were of him.

One highlight of the Glen Campbell Goodbye Tour was the Grammy's and another was our visit to Capitol Hill last year. My family and I came to Washington, DC along with the documentary filmmakers and the Alzheimer's Association to meet with many Senators and Representatives. This was last May when the first-ever National Alzheimer's Plan had just been released, and we were meeting with members of Congress to ask that they please make sure there was funding for the Plan. While we were here, we also played a special performance for members of Congress at the Library of Congress during a briefing put on by the Alzheimer's Association. It was amazing to see Senators and Representatives sing along with Dad and to know that they were fighting along side my family to end this terrible disease.

State of the Disease

Before my family was affected, I didn't realize what a serious disease Alzheimer's is or how many people were affected by it. Frankly, it's still hard to imagine how huge this problem is in America and all over the world.

Since my Dad's diagnosis, I have spent time with community members, policy makers, researchers, and physicians. While I am an actor and musician, I am also a dedicated Alzheimer's advocate and I would like to share with you some of what I have learned.

Alzheimer's is a progressive and fatal brain disorder. Over five million Americans are living with Alzheimer's today, with 200,000 under the age of 65.

According to the Alzheimer's Association, our nation is estimated to spend $203 billion in direct costs for those with Alzheimer's this year, including $142 billion in costs to Medicare and Medicaid. Average per person Medicare costs for those with Alzheimer's and other dementias are three times higher than those without these conditions. Average per senior Medicaid spending is 19 times higher. A primary reason for these costs is that Alzheimer's makes treating other diseases more expensive, as most individuals with Alzheimer's have one or more co-morbidity that complicate the management of the condition(s) and increase costs. For example, a senior with diabetes and Alzheimer's costs Medicare 81 percent more than a senior who only has diabetes.[1]

If nothing is done, as many as 16 million Americans will have Alzheimer's disease by 2050 and costs will exceed $1.2 trillion dollars (not adjusted for inflation) - creating and enormous strain on the healthcare system, families and the federal budget. In fact, an NIH-funded study in the *New England Journal of Medicine* confirmed that Alzheimer's is the most costly disease in America, with costs set to skyrocket at unprecedented rates.[2]

Currently, Alzheimer's is the sixth leading cause of death in the United States and the only one of the top ten without a means to prevent, cure or slow its progression. That there are not any treatments to really change the course of the disease is still shocking to many families, including mine.

With Alzheimer's, it is not just those with the disease who suffer -- it is also their caregivers and families -- and the data here is just as startling. In 2012, 15.4 million family members and friends provided unpaid care

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[1] Alzheimer's Association, 2013 Alzheimer's Disease Facts and Figures, *Alzheimer's & Dementia, Volume 9, Issue 2*

[2] Monetary Costs of Dementia in the United States, *New England Journal of Medicine 2013; 368:1326-1334*

valued at over $216 billion. More than 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high, with one-third reporting symptoms of depression. Caregiving also has a negative impact on health, employment, income and finances for countless American families. Due to the physical and emotional toll of caregiving on their own health, Alzheimer's and dementia caregivers had $9.1 billion in additional health costs in 2011.

Changing the Trajectory

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. NAPA mandated the creation of a strategic national plan to address Alzheimer's disease.

On May 15, 2012, the U.S. Department of Health and Human Services (HHS) released the first-ever *National Plan to Address Alzheimer's Disease*. The Plan established goals and action steps in the areas of research, care, support and public awareness in order to prevent and effectively treat Alzheimer's disease by 2025.

The Plan has made some progress in the fight against Alzheimer's including:

- Created a blueprint for Alzheimer's research at the National Institutes of Health (NIH), a much needed first step in setting priorities for Alzheimer's research.
- Expedited Food and Drug Administration (FDA) approval of drugs for early-stage Alzheimer's.
- Developed quality measures for dementia care in nursing homes.
- Enhanced dementia training for healthcare professionals.
- Promoted resources for caregivers through the creation of www.alzheimers.gov.

What's Needed Next?

The first year of the *National Plan to Address Alzheimer's Disease (The Plan)* has seen some great steps towards changing the trajectory of Alzheimer's disease, but there is still much work to be done. For two years, the Advisory Council on Alzheimer's Research, Care and Support has recommended a rapid ramp up in Alzheimer's research to at least $2 billion a year to take advantage of current scientific opportunities that will allow us to develop better treatments and prevention for Alzheimer's disease. In Fiscal Year 2014, NIH is expected to spend only $484 million on Alzheimer's research. This level of funding is no where near the $2 billion called for by the Council and it is fractions less than what our government is spending on Alzheimer's care. This means that for every $29,000 Medicare and Medicaid spends caring for individuals with Alzheimer's, the NIH spends only $100 on research to find treatments for Alzheimer's.

Understanding this, the President's FY 2014 budget request included $80 million for Alzheimer's research and $20 million for education, outreach and support. These funds are a critically needed down payment for needed research and services for Alzheimer's patients and their families.

With these funds, states will be able to improve dementia care services and supports, create greater public awareness campaigns to connect caregivers to community resources and provide better provider education and training. These steps will better prepare individuals with the disease and their caregivers while lengthening the ability to provide care in the home and community setting.

Ultimately, strategic research funding is the key to preventing human suffering and reducing the enormous costs related to Alzheimer's. Research is the only way to get to earlier diagnosis, preventive treatments or even a life-saving cure. We have seen the smart investments in research yield treatments that have saved individuals and the healthcare system millions while creating research and clinical jobs. If a treatment were developed that delayed the onset of Alzheimer's by just five years, it would cut government spending on care for people with Alzheimer's nearly in half. But to do so, we must give the scientists funds to do the job.

That is why I believe it is imperative for Congress to provide the resources necessary to implement the Plan, and why I ask you to support the President's FY 2014 budget request for $100 million for the Plan's implementation.

Conclusion

Music was always part of our home, and we're all still playing even if we are not on stage in the same way. We knew at the beginning that Alzheimer's doesn't rob you of the things you love right away. But, the disease keeps getting worse and there aren't any medications to stop it. For my dad that's been true as well. To truly fight this disease, we need your help.

I would like to thank the Committee again for the opportunity to share my story and support for the work being done to address Alzheimer's disease. I strongly believe in the Plan and the goal of preventing and effectively treating Alzheimer's disease by 2025. I am hopeful that the Congress will support the President's budget request of $100 million to ensure implementation of the Plan.