Testimony of Cheryll Woods-Flowers
Hearing on "Changing the Trajectory of Alzheimer's: Reducing Risk, Detecting Early Symptoms, and Improving Data"

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Chairman Collins, Ranking Member Casey and members of the Committee. Thank you for the opportunity to testify about my experiences as a caregiver for my late father. I hope my story will bring more awareness to this awful disease, called Alzheimer's.

My father, Richard Allen Novak Sr., passed away in February after living with Alzheimer's disease for nearly 16 years. When he was 18 ,my dad left his home in Wisconsin to join the U.S. Navy which lead him to Charleston, South Carolina where he would meet and fall in love with my mom. Dad worked hard throughout his career in the Navy and after retiring he worked in Civil Service, retiring in 1988, and then started a successful woodworking business. He was always willing to help anyone who needed him, sometimes without accepting payment. He will be remembered for his love of dogs, people, his amazing Christmas light display that always drew lines of cars, and his love for his family including his six children, 11 grandchildren and 14 great grandchildren.

Before my dad was diagnosed with Alzheimer's disease, it was not something that my family knew much about. My mom started noticing that dad seemed to be having trouble remembering where he left things, he was taking longer with errands and kept forgetting things he was supposed to be doing. In 2003, my parents took a trip to Florida which they had done many times before, dad left at 8am to get a tire fixed on the car and at about 4pm mom called us and said they couldn't find him. When we found him, he had been crying, hadn't eaten and didn't have any money. It was truly an eye-opening experience. After that, we knew we had to get help. We took him to a specialist at the Medical University of South Carolina and after a few cognitive tests, he was diagnosed with Alzheimer's. He was on Aricept and Namenda, both of which he continued to take until the end. He was diagnosed at age 70 and every day we lost a little bit more of him, including the last five years when he did not recognize his children, grandchildren or other family members. Though he didn't know us, he continued to express love to each person he encountered, showed gratitude when things were done for him and we were so happy to be around him.

In a way, we were lucky that my dad was diagnosed so early in the disease. According to the Alzheimer's Association, only about half of individuals living with Alzheimer's have been diagnosed. When people are diagnosed early in the disease, they have time to work with their family and physician to engage in care planning, talk through financial decisions, and discuss support services. My dad's early diagnosis gave us that time to talk through decisions, start interventions like medications to mitigate symptoms, and gave him a better quality of life because we knew what we were up against.

I believe it is important to make the public and health care professionals aware of the early signs of Alzheimer's disease. There needs to be a greater nationwide public health effort and infrastructure in order to increase early detection and diagnosis. Legislation like the BOLD Infrastructure for Alzheimer's Act will help to do that. It would create an Alzheimer's public health infrastructure across the country that would look to tackle certain Alzheimer's public health issues like increasing early detection and diagnosis. BOLD would accomplish these goals by creating Centers of Excellence across the country that would educate the public, public health officials and health care professionals on Alzheimer's, brain health and health disparities. It would work with state, local and tribal public health departments to implement interventions to increase early detection and diagnosis.

After dad was diagnosed, my sister, Theresa, and I were named his Conservator and Guardian. We were his primary family caregivers. We were only able to do that because we lived nearby and we had the funds to keep him home as long as possible. We sold the house that my dad bought 55 years ago in order to be able to pay for his care. About three years ago, we got to the point where it was time for him to live in an assisted living facility. We found a great facility nearby but it certainly did not come without significant expense. The average estimated lifetime cost of care for an individual living with dementia is over $340,000. In 2017, 16.1 milion family members and friends provided 18.4 billion hours of unpaid care to people with Alzheimer's and other dementias at an economic value of over $232 billion.

I do not believe there is a complete understanding of the cost of Alzheimer's disease on our society. Since 2011, Congress has worked in bipartisan fashion to nearly quadruple the funding for Alzheimer's and dementia research at the National Institutes of Health (NIH). We've made great strides but there is still so much further to go. Alzheimer's disease is the most expensive disease in America. In 2018, Alzheimer's and other dementias will cost the nation $277 billion and by 2050, those costs could be as high as $1.1 trillion. Research dollars are critical to solving this crisis that devastates families and will impact our economy.

I've always believed that it is never enough to sit around and wait on someone else to do something. If not me, then who? About 4 years ago, I became an advocate with the Alzheimer's Association. I've met with my congressman to talk to him about making Alzheimer's research, care and support a national priority. Every year since 2014, I participate in the Walk to End Alzheimer's because I want to be part of the effort to eradicate this disease.

These last few days, I joined more than 1200 advocates from across the country to make a difference here in Washington. We are here to advocate for the 5.7 million Americans living with Alzheimer's today, to raise awareness of the disease and to push for more research funding. Alzheimer's is the only leading cause of death in the U.S. that cannot be prevented, cured, or even slowed, but through medical breakthroughs we're working together to change that. I am here because I promised my dad that I would be his advocate and voice as long as I'm able to and also with hope that my children and grandchildren will not have to think about these issues because a cure will be found.

As a caregiver and advocate, I am respectfully asking Congress to continue to make Alzheimer’s research a priority and pass the BOLD Infrastructure for Alzheimer’s Act to help other families get diagnosed early.

This is my first father’s day without my dad. Thank you for listening to our story and for all you have done. Please continue to join us in the fight to end Alzheimer’s once and for all.