

# Making a Difference in the Fight Against Alzheimer's

For three days in late March, I was among hundreds of Alzheimer advocates from across the country who gathered in Washington D.C. to call attention to the 5.3 million Americans with Alzheimer's disease (AD). I, along with Courtney McDonald, administrator of the Michigan Alzheimer's Disease Research Center (MADRC), and Mary Ellen Geist, author and caregiver, was fortunate to have the support of the MADRC to be able to participate in the Alzheimer's Association's (AA) Public Policy Forum and visit our local Michigan senators and representatives on the Hill to convey the message that they must support policies that will result in a change in the trajectory of this disease.

According to the Alzheimer's Association's 2009 "Facts and Figures", released the week of my visit in D.C., there may be as many as 16 million Americans with AD by the year 2050, tripling healthcare costs for those age 65 and older, if change does not take place. I am familiar with the devastating toll that AD takes on individuals struggling with this disease and on their families, having experienced it in my own family and that of innumerable patients.

At a senate hearing chaired by U.S. Senate Special Committee on Aging Chairman Herb Kohl of Wisconsin, I listened to the release of the "National Strategic Plan" prepared by the Alzheimer's Study Group (ASG). The group's leaders including former Speaker of the House Newt Gingrich, former Senator Bob Kerry, and former Supreme Court Judge Sandra Day O'Connor presented recommendations of the plan to fund research to halt Alzheimer's disease as well as recommendations to improve support to families and caregivers including long term care policies.

Along with the reports from the ASG and the AA, I sincerely believe that the collective voices of the advocates were heard. I am hopeful that we can continue to raise awareness about the importance of ending this disease. I urge individuals to write to their state and national senators and representatives in support of the recommendations of the ASG.

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I decided to attend the 2009 Public Policy Forum in Washington D.C. for the simple fact that - like the more than ten million people across the U.S. taking care of someone living with Alzheimer's - I couldn't stand it anymore: my father, suffering with Alzheimer's disease for fifteen years; my mother's life and livelihood sapped away by being his caregiver for a decade and a half; the sorrow and sadness my two sisters and their families were experiencing due to the heartbreaking daily grief of my father's slow demise; and my own life - turned upside down- by quitting my job to come home to help my mother take care of my father four years ago. A similar story is being told over and over again by families across the U.S.. And so many families suffer much more than my family does. I decided I had to do everything within my power to help find a cure for the disease and help caregivers whose lives are often destroyed when their loved ones are diagnosed with the disease.

One of the most moving moments for me was when Maria Shriver and Sandra Day O'Connor delivered their address during the Senate Hearings. Maria, the executive producer for the documentary series called The Alzheimer's Project, which will air in May, talked about how much it hurt that her father no longer knew her name. That's what I had experienced with my father, too, and I felt linked to her in a new way. I felt honored that she had chosen to tell my father, Woody's, story (he is featured in one of the documentary series called "The Memory Loss Tapes") and I suddenly realized how important it was that his story will go out into the world to help others.

For the first time in a long while, hope filled the room.

I feel this is important work. I will carry it on as I tell my father's and my family's story throughout the coming months, and I hope to be back at the Public Policy Forum next year.

Mary Ellen Geist, a former broadcast journalist, is the author of the book "Measure of the Heart: A Father's Alzheimer's, A Daughter's Return". You can reach her at [maryellengeist.com](http://maryellengeist.com)

