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Inspiring Leaders, Technology and Cherry Blossoms: My Experience at the 2014 Advocacy Forum

Before I went to the Forum, I was hoping to learn more about effective advocacy, meet people passionate about Alzheimer's disease and observe the reaction of Legislators to our cause. I learned and experienced far more than I ever thought possible. I was deeply impressed with the scope of the Alzheimer's Association. I had heard the phrase "an international organization" but it was thrilling to see advocates of all ages from 49 states and the United Kingdom. The caliber of leadership we have is so outstanding and each one I met was approachable, friendly and extremely knowledgeable. The manner in which we were taught was efficient and interesting and used the latest in technology to help us understand how to advocate. I was especially interested in how Social Media is now being employed to spread the word about the need to find a cure for Alzheimer's. This will be a continuing study for me as I am well beyond the "techie" age, but I learned enough to get started. I also learned that the cost of Alzheimer's disease is even higher than what I initially thought. It is the most expensive disease in America and the cost is skyrocketing. At the current rate, our economy will be overwhelmed and Medicare and Medicaid will be bankrupt. Obviously this is an unsustainable situation; we all have to do what we can to foster awareness, education and research.

I was encouraged by seeing nearly 1,000 advocates and know that there are so many others working on this problem that even if I feel I am doing little, adding it to what others are doing could make a small difference. People were willing to share their stories, give their time and incur the expense because the termination of Alzheimer's is so important.

I was somewhat surprised to learn how quickly younger-onset is occurring and the effect it is having on our country. We heard children ages 13 and 17 speak on serving as part-time caregivers for their grandparents. There is an increasing number of Young Advocates and a movement across college campuses of these young advocates. I believe this is an exciting dynamic which will make a difference in the outcome.

On April 9, more than 800 people converged on Capitol Hill to speak to legislators and staff seeking support for the NIH request for \$200 million dollars for research in 2015, for the HOPE Act and for the Alzheimer's Accountability Act. I was surprised and pleased at the positive receptions we received everywhere we went. Visitors at the offices, as well as the elected officials and staff, stopped us to ask about our work and express interest in stopping Alzheimer's.

The Forum had provided us with excellent training and materials that were clear and easy to use in speaking with our assigned legislators and staff. While we did not receive a positive answer in every instance, we did receive many assurances of support and made a significant presence on Capitol Hill.

For the past two years I had considered going to the Forum and each time concluded that the cost outweighed the value. I was totally wrong. The experience for me was inspiring, educational and enjoyable. The speakers were some of the most outstanding in their fields, such as Dr. Collins, Director of the NIH, the director of the FDA, governors, senators, representatives and other such leaders. I have come back renewed in my commitment and determined to do what I can, though it be small, to help wage the war against this cruel and devastating disease. The goal is to find a way to prevent or cure it by the year 2025. I sincerely hope it will not be that long before we are living in a world without Alzheimer's. And I saw the cherry blossoms!!



Doris Sanders was a caregiver for her husband, a minister who passed away from Alzheimer's disease, and is currently an incredible Ambassador to Congressman Patrick E. Murphy (FL-18). She shares her thoughts on why advocacy is so important and what the Alzheimer's Association is doing to raise funds for research and awareness.