

Testimony on behalf of the Alzheimer's Association in front of the Joint PA House and Senate
Aging Committees

Kevin S. Tucker, Chair, Public Policy Coalition for PA's Alzheimer's Association Chapters

Tuesday, 24 June 2014

My sincere thanks to all of the chairs of both committees for calling this meeting to present the Pennsylvania State Plan for Alzheimer's Disease and Related Disorders to the General Assembly. The bulk of our work now lies ahead of us.

My name is Kevin Tucker, I chair the Pennsylvania Public Policy Coalition, an entity that speaks on policy matters for the Alzheimer's Association in PA. The Commonwealth is served by two chapters of the Association; the Delaware Valley Chapter covers Philadelphia and its five surrounding counties. The Greater PA Chapter serves the rest of the state and I serve on the board of directors for the Greater PA Chapter and as their Public Policy Committee Chair.

The mission of the Alzheimer's Association is a world without Alzheimer's Disease. It's also much more than that in that the Association provides programs and services aimed at educating, supporting, and curing the myriad disorders often referred to as "dementia". Together with our national organization, the two chapters in PA provide the following:

- A 24-hour helpline, 800-272-3900
- Early stage initiatives including support groups, education programs, and education services for the newly diagnosed
- Care consultation
- Trialmatch, a clinical trial matching service related to these disorders for anyone to participate
- Consumer education
- Professional education
- Diversity focus on various minority communities
- Caregiver support groups
- Safety services that provide 24/7 coverage for a person wandering or lost, vital medical information and education for our first responders
- Advocacy

Over **5 million Americans** are living with Alzheimer's, and as many as **16 million** will have the disease in 2050. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$214 billion** in 2014, increasing to **\$1.2 trillion** (in today's dollars) by mid-century. Nearly **one in every three seniors** who dies each year has Alzheimer's or another dementia.

Across the country, the Alzheimer's Association has been a champion for national and state plans. In December of 2010 the United States Congress unanimously passed the National Alzheimer's Project Act and it was signed into law by President Obama in January of 2011. This law required the creation of a national strategic plan to address the rapidly escalating Alzheimer's disease crisis and the coordination of Alzheimer's disease efforts across the federal government. Additionally, 33 other states and the District of Columbia have published their

own state plans. These plans and the national plan were all resources for the plan Secretary Duke is presenting to you today.

For me, personally, the experience of participating in the town halls, the executive committee meetings, and the public input sessions was an emotional one. My connection to Alzheimer's is well-documented on several records. My story is my father's story. My paternal grandmother suffered from what we now believe to have been Alzheimer's. My mother died in November of 2011 from dementia after having two brain tumor surgeries and radiation therapy. My father's brother died a week after my mom having suffered two strokes that led to his dementia and my father's sister is currently in the final stages of Alzheimer's Disease. Unfortunately, it doesn't end there. My father suffered a fatal heart attack in July of 2012 after having been my mother's primary caregiver. The stresses and pressures of caregiving takes an enormous toll on these individuals and is a focus of the State Plan and my personal charge in the effort.

As I stated at the beginning, with the presentation of this state plan, the bulk of the work now lies ahead of us. The plan calls for a strategic approach to the rabid epidemic Alzheimer's and the related disorders present to us. Through expanded awareness efforts, promotion of brain health, medical professional and emergency responder education, support for both professional and non-professional caregivers, and efforts to encourage research, the plan lays the groundwork for policies, programs, and even legislation to be created in the coming months and years. The Alzheimer's Association remains dedicated to helping breathe life into the Pennsylvania State Plan and doing all we can to ensure its success. Again, my thanks to both committees and the General Assembly as we begin this effort together.

Respectfully submitted,

Kevin S. Tucker

Chair, PA Public Policy Committee, Alzheimer's Association in Pennsylvania