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Good morning Mr. Chairman, and distinguished members of the House. My name is Bob Marino and I'm the Chair of the Pa. Public Policy Coalition, a Board Member and a volunteer Family Caregiver Trainer for the Delaware Valley Chapter of the Alzheimer's Association.

By convening this hearing you do great honor to our organization, but more importantly, to the nearly 500,000 afflicted Pennsylvanians currently struggling with this terrible disease or related dementia. We're VERY grateful! A special thanks to Rep. Crahalla for her initiative and leadership in facilitating this process.

We've assembled for you today an impressive panel of experts: Key executive & program staff from our Delaware Valley Chapter, clinicians, community leaders, caregivers, and direct beneficiaries of some of the many services that we provide, most at little or no cost. They will tell you a compelling story ---one of struggle and notable achievement against great odds and a relentless disease. Above all, they will also demonstrate in countless ways, how critical ongoing legislative financial support is in two key areas: the annual DOA budget allocation for Alzheimer's Outreach, and the Federal Administration on Aging (AoA) Alzheimer's Disease Demonstration Grant awarded to Pennsylvania in 2002.

To aid in our testimony today, I'd first like to offer a brief history & overview of our organization, its structure within the Commonwealth, a synopsis of our key programs & services and some alarming statistics that highlight why many consider Pennsylvania a "ground zero" state by the devastation wrought from this condition. I'll conclude with some specific information on the DOA budget allocation, how it's used, and why it's so crucial to our future success.

The Alzheimer's Association traces its genesis back to 1980 in the Chicago area, where a small, concerned group of caregivers first gathered to try and support one another through the terrible ordeal of a disease that most at that time hadn't even heard of. From that modest beginning, we have grown into a truly national organization with chapters in all 50 states and currently maintain our National Headquarters in Chicago. We also have a fully-staffed Public Policy office in Washington D.C. Make no mistake however, as with many non-profits, our true strength lies in a combination of surprisingly small numbers of truly dedicated professional staff "leveraged" with thousands of volunteers acting in multiple capacities, many or most having personal family experience with this tragic disease. Some of the finest people I've ever had the privilege of working with are in this remarkable cadre, many sitting beside or behind me this morning.

In Pennsylvania, after a recent reorganization, two state chapters represent us: The Greater Pa. Chapter, headquartered in Harrisburg, serves 57 counties in the Central, South-Central, Western & Northern Tier areas, while the Delaware Valley Chapter with its offices in Philadelphia, covers 8 counties in Southeastern Pa. (in addition to Southern New Jersey & Delaware) Our mission is simple, yet profound: to help people with Alzheimer's disease and related dementias and their families through education, advocacy and support. How do we accomplish such a mission? With some of the programs and services that I'll now outline.

A toll-free, 24/7 Contact Center / Helpline that has the capability of translating over 140 languages through a special service. In the Delaware Valley office, 3 ethnically matched helpline specialists are on staff daily. For a caregiver in crisis, this service might best be described as a literal "lifeline" in times of greatest need.

156 Support Groups across the Commonwealth, 78 in SE Pa. alone with dedicated sessions for African-American, Latino & Korean families as well as those struggling with the especially devastating reality of "early onset" dementia.

Family Caregiver Training for caregivers and family members held on successive evenings or Saturdays for a total of 8 hours of instruction on medical aspects of the disease, eldercare law and managing the all-important activities of daily living for someone with Alzheimer's or a related

dementia. Specialty sessions currently include African-American, and Spanish / Korean language versions and a prototype in Chinese.

Safe Return For Wanderers Program that places selected staff on 24/7 beeper service. Clients enroll in a National Database & wear ID jewelry so that they might quickly be reunited with family when unable to give their name and phone # after wandering from the home. The chapters provide family support and total interface with local police, media, and hospitals. This program saves lives and much heartache.

Our Multicultural Outreach Program in the Delaware Valley Chapter has been in place for over 12 years and is nationally recognized as a “benchmark” service of it’s kind for delivering programs and services to those who face significant cultural or language barriers.

Both state chapters also provide hundreds of “In-Service” Training Programs for professional caregivers in a variety of settings and a Speaker’s Bureau for business and community organizations interested in learning more about the disease. In addition, they maintain two websites and send out quarterly newsletters to further enhance disease education and outreach.

As I think you’ll agree, the Alzheimer’s Association is truly at the “front lines” of this battle, 24/7, 365 days a year, bringing hope, giving guidance, providing information, helping to coordinate care, and sometimes just being available to listen --- as an understanding and supportive partner.

Now, allow me to address why I used such a dramatic term as “ground – zero” earlier when describing Alzheimer’s disease and related dementias here in Pennsylvania, for the statistics are sobering indeed. Our best estimates point to nearly 500,000 citizens currently suffering with the condition or a related pathology. If no definitive cure is found, that will likely grow to nearly 2 million by 2050. An additional 1,200,000 Pennsylvanians are directly affected by caregiving duties or support for same. In addition to the obvious psychological toll, this also manifests itself as an alarming “ripple” across the economic vitality of the state as caregivers and other family members are forced to downsize themselves in their jobs and careers as the disease progresses or in some cases, leave the workforce entirely. The greatest at-risk population for Alzheimer’s disease and related dementias is also rapidly growing. Between the 1990 & 2000 National

Census, people aged 75-84 increased by 21% and those older than 85, the highest Alzheimer's risk segment, by 38%

Over the next ten years, the number of those aged 60 and older is projected to comprise nearly 25% of Pennsylvania's total population. We are indeed a state that is largely aging "in-place". The Commonwealth currently has the SECOND highest percentage of people over age 60 in the nation and the THIRD highest total number of rural elderly. Currently Pennsylvania spends nearly 4 BILLION dollars in Medicare/Medicaid funds for individuals with Alzheimer's disease and that is projected to grow to SIX billion by 2010. This brings me to my final point this morning, namely how & why we need your continued support for critical state funding. By providing all of the programs and services that I highlighted earlier, we firmly believe that we play a crucial role in keeping those afflicted with these diseases in place, at home for as long as possible which both they and their caregivers and loved ones so desperately want. By doing so, we help in delaying or deferring those unhappy and costly next steps of nursing home placement, thus lightening the emotional and financial toll of families and Pennsylvania taxpayers alike.

One specific and critical example of how the legislature does play a direct role in this goal is the annual Dept. of Aging budget allocation for Alzheimer's Outreach. These dollars formally appropriated through the Dept. of Health, were transferred to oversight of the Dept. of Aging in 1999. Up until the budget crisis of last year, the allocation was awarded in the amount of \$250,000 of which \$50,000 was kept in-house by the Dept. of Aging and \$200,000 passed on to the state chapters. In FY'04, that amount was drastically cut to just \$145,000 of which only \$100,000 was passed on to Greater Pa. & Delaware Valley. The net result was a full 50% cut to resources DIRECTLY used to fund those critical services outlined earlier. Detailed testimony that is being submitted today by our Greater Pa. Chapter Board Chair, Leslie Dunn will serve to illustrate some specific examples of how representative dollars of that allocation are spent. In short, for an organization of our size, this cut was a grievous blow indeed, forcing us to scramble for additional private-sector resources to make up the shortfall while trying to support an at-risk population growing significantly faster than much of the nation. Mr. Chairman, I urge you and your colleagues to strongly reconsider restoring those funds to pre-FY'04 levels

and also provide critically need state match dollars for our hard-fought Federal AoA Grant. I hope that my testimony and those that follow will aid in that decision. With your help, we'll be able to continue with and improve upon our common goal---- that of aiding some of our most vulnerable fellow-citizens.

Thank-You!