

## **Testimony**

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I am Wendy Campbell, President of the Alzheimer's Association Delaware Valley Chapter. Thank you for scheduling this Committee hearing on Alzheimer's. We very much appreciate this opportunity to present here today.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research. Our mission is to eliminate Alzheimer's Disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. There are 76 Chapters in the U.S.; two Chapters serve Pennsylvania.

The Delaware Valley Chapter serves the 8 counties of Southeastern Pennsylvania: Berks, Bucks, Chester, Lehigh, Montgomery, Northampton, and Philadelphia, as well as the 7 southern counties in New Jersey and the full state of Delaware. We have 4 offices in Pennsylvania, including 3 branch offices in Reading/Berks County, Cochranville/Chester County and Hellertown/Northampton County; our Headquarters is located at 399 Market Street in Philadelphia. The Chapter currently has a staff of 36, of which 22 are based in PA.

While local Chapters raise money to fund research, for the most part our focus is on providing the programs and services for those affected, and reducing the risk of Alzheimer's through promotion of brain health.

Our Programs and Services include:

Our central service is a free **24/7/365 Helpline** (800/272-3900) which provides information about Alzheimer's disease and related disorders; referrals to the entire range of services available in our service territory from skilled nursing facilities with dementia units to home care to the services provided by the various county Area Agencies on Aging; emotional support for those moments when caregiver stress is at a peak; crisis intervention including sending police; and utilizes a translation service with over 180 languages which allows our Helplines to serve all cultures. The Helpline has been described as a "lifeline" by many of our constituents. Perhaps this is because it provides access to the myriad of free services and educational programs provided by the Chapters.

**Support Groups** for both caregivers and those with the disease meet routinely throughout the counties. Some are for men only, some Latino, Korean, grandchildren, those with Fronto-temporal disorder, and others include the full range of family caregivers. These groups encourage members to share information, give or receive mutual support and exchange coping skills. Indeed in the past year there has been a **38% increase in support groups so that we now have over 220** in our service territory.

The **Medic Alert + Safe Return Program** registers participants in a National data base which can transmit photos and medical information to police and hospital emergency rooms in an increasing radius until the wanderer is found. All members of our clinical staff are trained in Safe Return and one is carrying a beeper 24 hours a day to help families in their search efforts, which often includes involving police and media in the search process. Over 60% of those with Alzheimer's disease will wander at some time during the disease process and some will wander repetitively. After 24 hours the odds for a safe return reduce dramatically. We train first responders from local to state police, fire and medical personnel in optimum dementia search and rescue techniques. This service is becoming increasingly important as recently we have had

3 wandering cases going at the same time within our service area in a single weekend as families struggle with the economic challenges of caring for their loved ones.

### **Newsletter**

The Chapter's Newsletter serves 80,000 with tips for caregiving, information about support groups, current research and treatment findings, legal and financial matters and news about Chapter events and programs. We are gradually adding email additions to increase frequency and reduce mailing costs.

Our **Learning Academy** includes educational programs for caregivers:

- Free 8 hour Family Caregiver Training workshop that prepares families for the long journey ahead when a family member is diagnosed with Alzheimer's or a related disorder by including 2 hours with a medical professional, 2 hours with a legal or financial specialist, 2 hours of safety training and 2 hours on communication.
- 1-2 hour programs on Basics of Alzheimer's, Early Stage Programming, specific behavioral issues, stages of the disease, memory enhancers, Brain Health, the National programs Maintain Your Brain, Partnering with your Doctor, Caregiver Stress, and over 50 other topics are offered throughout the community.

### **Professional Training**

These are fee-for-service workshops for professionals that can be facility-based or regional trainings to equip health professionals with the tools and skills necessary to provide quality care in nursing homes, assisted living facilities, hospitals, adult day centers, senior centers, and home health and hospice agencies. Courses are tailored to meet individual facility needs. We believe that every person (from administrator to nurse to aid to security guard) who is paid to take care of an Alzheimer's patient needs dementia specific training annually to provide quality care to someone with a progressive neurodegenerative disorder.

### **Care Consultation**

Our professional staff is dedicated to helping people navigate through the difficult decisions and uncertainties people with Alzheimer's disease or a related disorder face at every stage of the disease. We can provide Care consultation services by telephone, email or in person. Services range from assessment of needs, assistance with planning and problem solving, and supportive listening.

### **Early Stage Coordination**

For over a year we have had an Early Stage Coordinator facilitating programs and trainings for those who have recently been diagnosed. We have had to initiate telephone support groups to meet the urgent needs of these couples. This service is barely keeping pace with referrals now. We expect demand to grow rapidly as the baby boomers begin to reach 65.

### **Arts and Culture Program**

The Chapter's Arts and culture program ranges from Memories in the Making art classes for those in the mid-stage of Alzheimer's who need assistance with communication to offering group programs at local museums, theaters and other cultural settings (Philadelphia Art Museum, Mann Music Center, Longwood Gardens etc) where we have trained their staff to work with groups of Alzheimer's patients and their care partner.

I suppose you are wondering just how this volume of services are provided by a staff of just 36 as we attempt to serve the 294,000 who have Alzheimer's or a related disorder in our territory. We stretch our staff resources by **utilizing 1280 active volunteers in FY 2009 which provided over 1 million dollars worth of volunteer hours.**

Our budget is approximately \$4.5 million, of which only \$100,000 is from the Commonwealth. Over 95% of our services are free to our

families. About 80% of our funds are raised by individuals. Some funds are from memorials, tributes, general donations, bequests, workplace campaigns and the remainder from our multitude of events. The Alzheimer's Association signature awareness and fund raising event are the Memory Walks which take place throughout the US in the fall. Our last Walk is at Citizens Bank Park on Sunday morning, November 15 and I invite you all to participate. You will be joining over 7000 walkers who believe that Alzheimer's is one of the largest public health crises facing the US and that the time to act is now.

Thank you for the opportunity to present a brief overview of our Chapter Services.