



PENNSYLVANIA  
STATE PLAN FOR

ALZHEIMER'S  
DISEASE AND  
RELATED  
DISORDERS

FEBRUARY 2014



COMMONWEALTH OF PENNSYLVANIA  
DEPARTMENT OF AGING  
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February 7, 2014

The Honorable Tom Corbett  
Governor  
Commonwealth of Pennsylvania  
225 Main Capitol Building  
Harrisburg, PA 17120

Dear Governor Corbett:

The Pennsylvania Alzheimer's Disease Planning Committee extends its gratitude to you for your commitment to Pennsylvanians living with and impacted by Alzheimer's Disease and Related Disorders (ADRD).

On behalf of the Pennsylvania Alzheimer's Disease Planning Committee, and in accordance with Executive Order 2013-01, I am pleased to present the Pennsylvania State Plan on Alzheimer's Disease and Related Disorders containing recommendations to define a response to the current and anticipated growth in the number of Pennsylvanians living with Alzheimer's Disease and Related Disorders.

An estimated 280,000 commonwealth residents are living with Alzheimer's disease and the number is closer to 400,000 when adding in those living with related disorders. According to the Pennsylvania Department of Health, over 35,000 deaths in Pennsylvania have been caused by Alzheimer's disease during a ten-year period. As the population of older Pennsylvanians continues to grow, it is anticipated that the number of Pennsylvanians living with ADRD will increase.

The members of the committee included a Pennsylvanian living with Alzheimer's disease, representatives of families and caregivers of persons living with ADRD, providers from across the care continuum, elected officials and leading researchers.

For the past eight months, the committee worked to examine the needs and research trends, study existing resources, develop an effective response strategy to the rising number of those affected by the disease, and deliver these recommendations. The committee played a significant role in bringing public awareness to this growing crisis and how we, as a commonwealth, should

address the multitude of issues raised and the many challenges it creates for those living with ADRD.

Over 100 Pennsylvanians testified at six regional public meetings and over 330 comments were received through an online survey, correspondence and comments offered at five full committee meetings. The committee was inspired by the information received which helped form the framework for the recommendations.

The committee discovered the strength of existing resources and the potential for amplifying a response through partnerships. The plan submitted includes recommendations which emphasize the concurrent needs to enhance public awareness, support Pennsylvanians living with ADRD and their caregivers, educate healthcare providers and foster research.

I wish to thank all members of the Committee for their dedication; our fellow Pennsylvanians who shared their experiences and suggestions; advisors who provided guidance on key topics; the Alzheimer's Association Chapters of Pennsylvania for providing infrastructure support and the staff of your office and of the Pennsylvania Department of Aging.

Gratitude is also offered to members of the House Alzheimer's Caucus, the House Aging and Older Adult Services Committee and its staff, the Senate Aging and Youth Committee and its staff and legislators who attended public regional meetings for their interest and contributions.

When signing the Executive Order calling for this important endeavor, you recognized the challenges faced by fellow Pennsylvanians living with ADRD and the strength of our commonwealth. The Plan submitted includes recommendations with the potential to define a course of action that will set Pennsylvania apart in increasing awareness; improving care delivery; building a workforce and maximizing development opportunities in pursuit of a cure.

The committee and department look forward to continuing Pennsylvania's place as a national leader in ADRD research and care through implementation of these recommendations.

Sincerely,



Brian M. Duke

Chairman, Pennsylvania Alzheimer's Disease Planning Committee  
Secretary, Pennsylvania Department of Aging

**Pennsylvania (PA) State Plan for Alzheimer's Disease and Related Disorders (ADR):**

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# **I. Executive Summary**

## **Pennsylvania Plan for Alzheimer’s Disease and Related Disorders**

### **Introduction**

Governor Tom Corbett issued an Executive Order (Appendix A) on February 7, 2013 calling for the creation of the Pennsylvania Alzheimer’s Disease Planning Committee (committee). The purpose of the committee was to create, for consideration of the Governor, a comprehensive plan for a thoughtful, integrated and cost-effective approach to address the needs of persons living with Alzheimer’s Disease and related disorders (ADRD). Twenty- six commission members, comprised of legislators and stakeholders, were appointed for their expertise and leadership from across the ADRD care and research spectrum.

### **The Planning Process**

The Secretary of the Department of Aging, chaired the committee. Legislative members included the majority and minority chairpersons of the Aging and Youth Committee and Public Health and Welfare Committee of the Senate, and majority and minority chairpersons of the Aging and Older Adult Services Committee and Health Committee of the House of Representatives.

The committee began its deliberations in June 2013 in Harrisburg. This was followed by a series of six regional public meetings across the state between July and September, and an additional five meetings of the full committee between October, 2013 and January 2014. The committee’s workgroups met via teleconference between July and December, crafting a set of recommendations, goals, and strategies, which were subsequently compiled into an overall framework for the Plan.

Public input was gathered through public meetings, an online survey and correspondence. A total of 336 individuals shared their experiences, expertise, suggestions, and concerns, guiding and inspiring the work of the committee and ensuring that the needs of patients and caregivers remained at the forefront of its deliberations. Three themes emerged from the public comments:

- The experiences of persons living with ADRD and their caregivers, and the need for additional funding to support individuals, caregivers, health care providers, home and community-based services, long-term care, training, education, and research.
- The need to enhance awareness among the public to overcome stigma and promote the safety of persons living with ADRD.
- The lack of access to information that would help persons with ADRD and caregivers navigate the healthcare system and obtain legal, financial, and insurance support.

### **The Committee’s Charge**

- Examine the needs and research the trends in the Pennsylvania Alzheimer’s population;
- Study existing resources for addressing the needs of person with ADRD, their families and caregivers;
- Develop a strategy to mobilize the commonwealth’s response to the anticipated increase in incidence of ADRD in Pennsylvania; and,
- Submit recommendations to the Governor.

### **Examining the needs and trends in the Pennsylvania ADRD population**

Pennsylvania has the fourth highest percentage of elderly population in the nation, with the incidence of ADRD rising in line with the aging of the population. Over 400,000 Pennsylvanians are likely afflicted with ADRD, and the toll of the disease extends beyond those affected to their families, friends, and communities. All told, one in 12 Pennsylvania families is affected by ADRD.

Pennsylvania is not only one of the oldest states, but also one of the most rural. Rural Pennsylvanians are, on average, older, poorer, and with greater health care needs than those in urban areas, yet there are fewer primary care providers, nursing homes, and home and community-based services available. Racial, ethnic, and cultural diversity is also on an upward trend in Pennsylvania, and many of these population groups are at increased risk of developing ADRD yet have reduced access to care.

Pennsylvanians with ADRD have increased care needs across the continuum of the disease, yet appropriate care may not be available to all Pennsylvanians, particularly those in rural areas, those with unique care needs based on social and cultural factors, and individuals with younger onset ADRD. There is also a need to support caregivers.

### **Studying existing resources for addressing the needs of person with ADRD, their families and caregivers**

Increased care requirements come at a high cost that is borne both by the commonwealth and the families themselves. Many resources are available to assist individuals with ADRD, their families, and caregivers, yet accessing these resources can be challenging. The committee has compiled an initial list of these resources (Appendix D). The committee also recommended a series of strategies to make these resources more accessible to Pennsylvanians.

Among Pennsylvania's resources is the presence of world-class research institutions. Potentially ground-breaking research is conducted at Pennsylvania's two National Institutes on Aging-funded Alzheimer's Disease Research Centers and at many other universities and colleges across the state. In recent years, there has been a growing trend of building partnerships not only across academic institutions but with pharmaceutical, diagnostic, and biotech companies as well. Pennsylvania is thus well positioned to build upon its strong base in research and technology not only in the pursuit of improved care and treatment for people with ADRD but as an engine for economic development.

### **Developing a strategy to mobilize the commonwealth's response to the anticipated increase in incidence of ADRD in Pennsylvania**

The committee established three workgroups to address the major issues confronting the commonwealth: 1) Prevention and Outreach, 2) Healthcare Delivery and Workforce, and 3) Research and Metrics. The workgroups crafted a set of recommendations, goals, and strategies, which were subsequently compiled into seven overall recommendations. The recommendations are listed not in order of importance but emphasize concurrent needs to build public awareness, support individuals affected by the disease and their caregivers, educate health care providers who provide care across the continuum of the disease, and foster research which discovers cures, treatments, and prevention strategies.

The committee discussed the terms dementia and ADRD. In recognition of the evolution in diagnostic terminology used by clinicians and other care providers, the term ADRD encompasses the wide range of disorders associated with cognitive and functional impairment, and was thought by many members of the committee to be more respectful and less stigmatizing than the word dementia. At the same time, the committee recognized that limited use of the word dementia is appropriate in some cases and that raising awareness and understanding of these disorders is the only way to truly combat stigma.

### **Submitting recommendations to the Governor**

The committee reached consensus to recommend to the Governor the following steps:

- 1. Improve awareness, knowledge, and sense of urgency about medical, social, and financial implications of Alzheimer’s disease and related disorders (ADRD) across the commonwealth.**
- 2. Due to the magnitude of the ADRD epidemic, identify and where possible, expand financial resources to implement this plan through federal, state, foundation, private and other innovative funding mechanisms and partnerships.**
- 3. Promote brain health and cognitive fitness across the life cycle from birth onward.**
- 4. Provide a comprehensive continuum of ethical care and support that responds to social and cultural diversity, with services and supports ranging from early detection and diagnosis through end-of-life care.**
- 5. Enhance support for family and non-professional caregivers and those living with ADRD.**
- 6. Build and retain a competent, knowledgeable, ethical, and caring workforce.**
- 7. Promote and support novel and ongoing research to find better and effective cures, treatments, and prevention strategies for ADRD.**

The committee recognizes that developing the Plan represents an initial step in the process of responding effectively for Pennsylvanians living with ADRD. Government cannot accomplish this on its own – it will require committed partnerships energy, cooperation, creativity, and hard work of individuals, healthcare and social service providers research institutions, advocacy organizations, and industry. The committee looks forward to the implementation of this plan.

## II. Introduction

### **The Alzheimer's Disease and Related Disorders Epidemic**

Alzheimer's disease and related disorders are brain disorders that cause memory loss and other cognitive impairments in an estimated 5.2 million Americans [1], with the number expected to triple by 2050 [2]. These diseases are progressive, incurable, and fatal, leaving persons unable to care for themselves and unaware of the world around them. Currently the 6<sup>th</sup> leading cause of death in the United States and the 5<sup>th</sup> among those over the age of 65, it is the only cause of death among the top 10 for which there is no cure and no way to prevent or slow its progression. Moreover, as deaths from heart disease, stroke, and cancer declined between 2000 and 2010, deaths from ADRD increased by 68 percent[1].

Between 60-70 percent of those living with a related disorder have Alzheimer's disease itself. Other diseases that are captured under the umbrella of ADRD include Vascular Dementia, Dementia with Lewy Bodies (DLB), Frontotemporal Lobar Degeneration (FTLD), and mixed dementias [3]. These various disorders affect different parts of the brain, result in somewhat different symptoms, and may follow different trajectories. In this Plan, the term ADRD encompasses the totality of progressive neurological disorders that cause cognitive and memory impairment, behavioral and psychiatric problems, loss of the ability to care for oneself, and ultimately death.

Older age is the greatest risk factor for ADRD. Today, approximately 5 percent of Americans between the ages of 65 and 74 have ADRD, but the incidence increases dramatically after about age 74. Of those 85 years of age and older, about one-third have some form of dementia [4]. Over the coming decades, the segment of the U.S. population over age 65 is expected to increase from about 13 percent in 2010 to 19 percent in 2030 as the baby boom generation reaches old age [5]. With this aging of the population, the number of those with ADRD is expected to skyrocket as well.

Younger people can also be affected. An estimated 4 percent of those diagnosed with ADRD are under the age of 65, many of them in their 50s and 40s, and even 30s [6]. Women are more likely than men to have ADRD, in large part because women live longer than men. Hispanics and African Americans also have a higher incidence of ADRD [7, 8] and more severe cognitive impairment than whites, and Hispanics also have an earlier age of onset [9]. These racial differences may, in part, be explained by a higher incidence of other health conditions such as cardiovascular disease and diabetes, which are more prevalent in African Americans and Hispanics.

The monetary costs of caring for people with ADRD are expected to rise exponentially along with the increased prevalence. In 2012, the costs of health care, long-term care, and hospice care for people with Alzheimer's and other forms of dementia were estimated nationally to total \$200 billion, which includes \$140 billion for Medicare and Medicaid [1]. A large proportion of individuals with ADRD also have other medical conditions such as heart disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease, cancer and neuropsychiatric complications (e.g. psychosis, depression). The coexistence of these conditions with ADRD

results in higher costs, more hospital and skilled nursing facility stays, and increased use of home health care and hospice care.

In addition to the high medical costs associated with caring for people with ADRD, there are additional costs borne by unpaid caregivers. In 2012, more than 15 million Americans provided an estimated 17.5 billion hours of unpaid care to people with ADRD [1]. Compared to caregivers of other older people, caregivers of people with ADRD are more likely to provide assistance with activities of daily living such as getting in and out of bed, bathing, dressing, getting to and from the toilet, and feeding. They also frequently must manage medications and finances and deal with problematic behaviors. The economic value of this care has been calculated to be over \$216 billion [1]. But there are other costs to caregivers, such as out-of-pocket costs and lost productivity at work that are not accounted for in this calculation. Moreover, caregivers of people with ADRD report high levels of both emotional and physical stress that can take a toll on their own physical and mental health [10].

### **The National Alzheimer's Project Act (NAPA) and the National Plan**

In December 2010, the U.S. Congress unanimously passed the National Alzheimer's Project Act, which was signed into law by President Obama in January 2011. The law required the U.S. Department of Health and Human Services to craft and annually update national strategic plan to address the ADRD epidemic and to coordinate efforts across the federal government. The law also established an Advisory Council on Alzheimer's Research, Care and Services with both federal and non-federal representation, including caregivers, patient advocates, health care providers and researchers.

The first national plan to fight Alzheimer's Disease was presented in May 2012 at the Alzheimer's Research Summit, and was updated in 2013 [11]. The plan set forth five goals: 1) Prevent and effectively treat Alzheimer's Disease by 2025, 2) Optimize care quality and efficiency, 3) Expand supports for people with Alzheimer's Disease and their families, 4) Enhance public awareness and engagement, and 5) Track progress and drive improvement.

The National Plan recognized that States are on the frontline of the battle against ADRD, ensuring that care is available for those with the disease and providing resources and support for family caregivers. Thus, the National Plan called for coordination with states across a number of goals, including raising awareness about ADRD and cognitive health, supporting caregivers, and developing capable and culturally competent workforces. Pennsylvania is joining other states in developing a state specific plan to address the ADRD epidemic.

### **A Call to Action by Governor Corbett**

In February 2013, Governor Corbett signed an Executive Order establishing the Pennsylvania Alzheimer's Disease State Planning Committee, which was charged with developing a state plan to address the growing ADRD epidemic in the commonwealth. The Secretary of the Department of Aging was asked to chair the committee. Recognizing the ongoing concerns of the Legislature and the commitment of the House Alzheimer's Caucus, the Governor appointed the majority and minority chairs of the Senate Aging and Youth Committee and Public Health and Welfare Committee, and the House of Representatives Aging and Older Adult Services Committee and Health Committee. The Governor appointed 17 additional members to the committee,

representing persons with ADRD, caregivers, family members, representatives from the nursing home, assisted living, personal care home, adult day-care services, home care, and hospice industries, representatives from the medical care provider community, the statewide Alzheimer's Association chapters, a senior center, the Area Agencies on Aging, and the Pennsylvania Departments of Health and Public Welfare; and AD researchers. Non-voting advisors also provided additional expertise.

### **III. Alzheimer’s Disease and Related Disorders in Pennsylvania**

#### **Demographics of ADRD in Pennsylvania**

As many as 400,000 Pennsylvanians over the age of 65 are likely afflicted with ADRD, with the number expected to increase markedly in the coming years as a result of the aging of the population. Currently, Pennsylvania has the fourth highest percentage elderly population in the nation, with over 2.7 million residents over age 60 and more than 300,000 over age 85. By 2030, the number of Pennsylvanians over age 60 is expected to climb to about 3.6 million, an increase of over 30 percent [12].

Pennsylvania is not only one of the oldest states, but also one of the most rural, with the population of nearly 12.8 million people stretched across 19 urban and 48 rural counties, anchored by two major metropolitan areas in Philadelphia and Pittsburgh. Rurality contributes to a rich diversity among Pennsylvanians but also presents challenges with regard to providing appropriate care and support for individuals with ADRD and their families. Rural Pennsylvanians are, on average, older, poorer, and with greater health care needs than those in urban areas, yet there are fewer primary care providers, nursing homes, and home and community-based services available. In 2008, for example, there was one rural primary care physician for every 1,507 residents, compared with 1,981 in urban counties [13]. Geographic distance to specialty care for ADRD places an additional burden on rural residents.

Racial, ethnic, and cultural diversity is also on an upward trend in Pennsylvania, with the population of both Hispanics and African Americans increasing over the last decade and expected to continue to increase in the coming decades. Both of these population groups are at increased risk of developing ADRD.

Also at especially high risk of developing AD are individuals with Down syndrome. By age 70, about 50-70 percent of people with Down syndrome will have dementia [14]. During the public hearings, other population groups, representing those with an intellectual disability, those in the deaf community, those in the lesbian, gay, bisexual, and transgender (LGBT) community, expressed concerns regarding additional barriers in getting appropriate care.

ADRD not only affects older persons but also people in their 40s and 50s in the midst of building careers and families. Precise figures on the prevalence of early onset ADRD in Pennsylvania are unavailable; however, based on estimates of 220,000 to 640,000 Americans under the age of 65 affected by these disorders [6], it is likely that between 17,000 and 49,000 Pennsylvanians have early onset ADRD. These individuals face a number of common problems, including difficulty of getting an accurate diagnosis, loss of employment, difficulty obtaining financial assistance from federal disability programs, loss or lack of health insurance, and high out of pocket costs for medical and long-term care [6]. The Plan is designed to respond to the varying needs of all these diverse groups of people.

#### **Challenges of ADRD on Pennsylvania**

According to the National Center for Health Statistics, 3,591 Pennsylvanians died in 2010 from AD. The Pennsylvania Department of Health (PADOH) reported that over 35,000 deaths in Pennsylvania have been caused by Alzheimer’s disease during a ten-year period (2000-2010).

These numbers, however, may underestimate how many deaths are attributable to ADRD for many reasons, among them that most people with ADRD are older and have multiple conditions that may contribute to their deaths; that many cases of ADRD go undiagnosed; and that lack of standardization in the way deaths are recorded means that ADRD may simply not be listed on the death certificate as a cause of death even though it may have played a major role [15]. One recent study concluded that among Medicare participants in the United States, dementia was second only to heart disease as a contributing factor in the older adults with multiple diseases [16].

Beyond the increase in mortality, ADRD causes great suffering among those affected as a result of its slow and progressive nature. People with ADRD are three times as likely as cognitively normal elders to require hospitalization [17], and, as the disease progresses from memory loss and confusion to the inability to care for oneself and communicate with others, patients need increasing levels of care, often in a long-term nursing facility. The burden on these people is exacerbated by the stigma associated with these diseases, which are poorly understood, under-recognized and under-diagnosed, and may cause behavioral and psychological problems. Depression, for example, is a substantial problem among people with ADRD, particularly in the earlier stages, and may complicate diagnosis and treatment.

The additional health care needs come at a high financial cost. Medicare and Medicaid cover much of the medical costs of care, but other expenses may be substantial. Given that the average Social Security payment for a retired older Pennsylvanian in 2007 was \$12,900, less than 75 percent of what was needed to cover basic expenses; it is easy to see how the financial burden of providing care can wipe out a person's savings. The burden is even heavier for those 8.4 percent of Pennsylvanians 65 years of age or older who were living in poverty between 2008 and 2012 [18].

People living alone with ADRD, without family members to assist in their care, are at particularly high risk of problems in both obtaining quality care and paying for it. Depending on their housing, health and other circumstances, elders living alone in Pennsylvania need between \$14,012 and \$23,386 to cover basic living costs [19]. Social Security is the only source of income for one out of four retired elders living alone in the state. People who develop ADRD before they reach retirement age are also likely to face financial hardship due to loss of employment and inadequate insurance.

ADRD exacts a substantial burden not only on those affected but on their families, friends and communities as well. An estimated 667,000 Pennsylvanians provide unpaid care valued at nearly over \$9 billion for people with ADRD [1]. The toll on family caregivers is enormous - emotionally, financially, and on their overall health. All told, one in 12 Pennsylvania families is directly affected by ADRD.

### **Caring for Pennsylvanians with ADRD**

The care individuals require varies across the continuum of the disease. Primary care providers are on the front line when memory loss or other symptoms first become apparent, yet multiple studies show that many, if not most cases of ADRD, are unrecognized in clinical practice [20]. As a result, most people are not diagnosed until they reach the moderate or severe stages of the disease [21]. The Medicare Annual Wellness Visit now has a mandate to screen for cognitive

impairment, and a number of screening instruments have been developed, yet there is no consensus about which of these instruments is most useful or if there is an actual benefit to screening [21].

Referral for clinical evaluation to a memory clinic, geriatrician, geriatric psychiatrist, neurologist, or neuropsychologist specializing in ADRD may come next. However, Pennsylvania, along with the rest of the nation, is already experiencing a shortage of geriatricians, geriatric psychiatrists and geropsychologists that is projected to get worse in the coming years. Moreover, the entire health care workforce, including direct care workers such as nursing aides, home health aides, and personal care aides, receives very little geriatric training, according to the Institute of Medicine (IOM) [22]. The geriatric mental healthcare workforce, in particular, is too small to provide for the increasing care needs of people with ADRD, requiring a shift in thinking about how such care is delivered and by whom [23,24].

Many studies have shown that people with ADRD overwhelmingly wish to live independently and at home as long as possible. Home-based care also offers a much more affordable option for many people with ADRD [23]. However, if home care is no longer feasible due to the functional and cognitive loss of the person, safety issues, or other concerns, assisted living, personal care, or nursing facilities may be needed.

Approximately 70 percent of Pennsylvanians with ADRD live at home [24]. The Pennsylvania Department of Aging offers home and community-based services through funding provided by the Pennsylvania Lottery. Services can be accessed through the Area Agencies on Aging and include information and assistance, personal care, Adult Day Centers, transportation services, respite care, caregiver support, support groups, counseling, home delivered and congregate meals, senior community centers and insurance counseling.

In addition there are 261 licensed Adult Day Services Centers statewide, but 14 rural counties have no such centers[25]. Pennsylvania is home to 1,930 licensed home health and home care, hospice providers that offer home and community based services through Medicare, Medicaid, private and long-term care insurance.

Pennsylvania has over 140,000 residents in over 2,200 personal care homes and skilled nursing facilities. Some assisted living, personal care homes and skilled nursing facilities have separate memory care units. Two-thirds of Pennsylvanians residing in skilled nursing facilities have some degree of cognitive impairment, and about 40 percent have moderate to severe cognitive impairment [1].

### **Financing of Care**

The cost of care for individuals with ADRD tends to be much higher than for individuals with other chronic health problems because they tend to be older, have other coexisting conditions, and have more severe functional impairments that limit their ability to care for themselves [28]. Paying for this care typically requires a combination of self-pay, private insurance, and government assistance (Medicare, Medicaid, and Veteran's Affairs programs). There are limitations in coverage provided by insurers and government programs, causing the costs to fall to families. For example, a recent national study showed that yearly out of pocket spending for

people with dementia averaged over \$6,800 per person, 30 percent more than costs paid by Medicare [28].

Medicare, the nation's largest health insurance program, provides a level of coverage for people 65 and older and for people under 65 with certain disabilities. There are four parts to Medicare: Part A (hospital insurance), Part B (medical insurance), Part C (Medicare Advantage), and Part D (prescription drug coverage). Individuals who are already receiving Social Security or Railroad Retirement benefits when they turn 65 will automatically be enrolled in Medicare. Medicare recipients may also purchase supplemental insurance to fill in some of the gaps in Medicare coverage. In Pennsylvania, approximately 2 million individuals receive Medicare benefits [25].

PACE (Pharmaceutical Assistance Contract for the Elderly), PACENET (Pharmaceutical Assistance Contract for the Elderly Needs Enhancement Tier), PACE Patient Assistance Program, and PACE plus Medicare are Pennsylvania's prescription assistance programs for older adults, offering low-cost prescription medication to low income residents, age 65 and older. There are currently 25,000 PACE enrollees with ADRD. Under PACE Plus Medicare, PACE/PACENET coverage is supplemented by federal Medicare Part D prescription coverage and offers older Pennsylvanians the best benefits of both programs. Older adults continue to receive the same prescription benefits while, in many cases, saving more money. Over 300,000 Pennsylvanians receive prescription drug programs through PACE/PACENET.

Medicaid provides health and long-term care services for low income older adults and persons with disabilities. In Pennsylvania, this program is called Medical Assistance and is administered by the Department of Public Welfare. To qualify for coverage in Pennsylvania, residents must meet income and resource limits and fit into an eligibility category. The state spends \$4.7 billion annually on Medicaid long-term care services. In Pennsylvania over 235,000 older individuals receive Medical Assistance [25]. Medical Assistance is the predominate payer for long-term services and supports. The state serves individuals with ADRD through three main programs:

- Medicaid State Plan services for health care and prescription drug coverage
- Waiver Programs (primarily the Aging Waiver) for in-home long-term care services
- Nursing Facilities for institutional long-term care services

Individuals may purchase a long-term care insurance policy, which may cover nursing facility care, assisted living, home-health, respite care, palliative care, personal care, care coordination and adult day care. Long-term care insurance is regulated by the Pennsylvania Insurance Department. Age is not a determining factor in needing long-term care. When an individual requires assistance to perform the basic functions of dressing, bathing, eating, toileting, transferring, and walking, the purchased insurance provides a wide range in cost and coverage for these services.

Self or private pay refers to expenses paid by the consumer, including out-of-pocket expenses and services that are not covered by insurance policies or other government reimbursement programs. Self-pay patients typically are charged more than government insurance programs would be charged for the same service.

In summary, the ADRD in Pennsylvania is exacerbated by multiple factors: An aging and increasingly diverse population, including growing numbers of persons at elevated risk for ADRD; a large proportion of the population living in rural areas where there are fewer health care providers and other resources for persons with ADRD and caregivers; the paucity of clinicians trained in geriatrics and ADRD; and the high cost of care borne by individuals, their families, and the commonwealth. These challenges require a comprehensive response that mobilizes the residents of Pennsylvania, physical and behavioral health care providers, public and private organizations that provide psychosocial services to care providers, research and technology development institutions and companies, and governmental and public agencies that serve the people of the commonwealth.

### **ADRD Research, Technology, and Drug Development in Pennsylvania**

Pennsylvania boasts a strong and vital research and development community comprised of a large number of academic institutions, biotechnology, biomedical and pharmaceutical companies, many with a major emphasis on brain diseases. In their search for improved treatments and cures for ADRD, these organizations provide hope to the millions of persons affected by these diseases. Moreover, they represent an opportunity for economic development in the commonwealth.

ADRD research in the United States is funded primarily by the National Institute on Aging (NIA) of the National Institutes of Health. In 1984, the NIA established five Alzheimer's Disease Centers (ADCs) across the country to advance clinical care, conduct research and train health care providers in the care of persons with ADRD. Today there are 27 ADCs, two of which are located in Pennsylvania, at the University of Pennsylvania in Philadelphia and the University of Pittsburgh. Like other ADCs, the two Pennsylvania ADCs collaborate with other academic research groups and pharmaceutical, biotechnology, and diagnostics companies across the country [26]. In addition to the ADCs, there are a multitude of other academic institutions in the commonwealth contributing research towards understanding ADRD. Thus, they play a substantial role in advancing knowledge and developing new treatments and diagnostic technologies. In so doing, they not only improve the care of patients but also drive economic development in the commonwealth. Enhancing these collaborations, particularly by including research institutions, companies and health care organizations could fuel even greater research and economic benefits to Pennsylvania.

The Pennsylvania ADRD Plan envisions building on the research strengths already present to enhance the commonwealth's position as a major center and magnet for ADRD clinical research. This approach offers the opportunity to expedite research toward better treatments, provide jobs for Pennsylvanians, and to encourage economic development.

## **IV. Crafting a Plan for Pennsylvania**

### **Guiding Principles**

The Pennsylvania Alzheimer's Disease Planning Committee through the receipt of comments and suggestions from the public and through its deliberations identified several guiding principles that are offered as the context of the plan is understood.

### **A Plan for All Pennsylvanians**

*All populations are considered including diverse cultural, ethnic, socioeconomic, sexual orientation, gender, age and underserved groups.*

During dialogue with the residents of Pennsylvania the committee heard from representatives of the diverse communities that comprise Pennsylvania. Among those who spoke with the committee members and among issues shared by the work groups of the committee concerns and suggestions were presented that emphasized the lived experience of persons from communities of diversity. This included communities of culture and ethnicity; disability; age; sexual orientation; socioeconomic status; functional ability; the deaf community and the stages of living with Alzheimer's disease and related disorders,

The Pennsylvania Alzheimer's Disease Planning Committee considers the recommendations, goals and strategies as applicable to all Pennsylvanians living with or impacted by Alzheimer's disease and related disorders.

### **A Plan for All Areas of Pennsylvania**

*All geographic locations within the commonwealth including rural and urban areas.*

Pennsylvania is the nation's sixth most populous state. Residents live in urban, suburban, rural and frontier communities. As the committee considered the scope of the recommendations presented, it was cognizant of the need to address the concerns and suggestions of residents living in more populated areas of the state as well as address unique challenges associated with living in the more rural areas of commonwealth.

Pennsylvania is the second most rural state in the nation. According the U.S. Census Bureau, nearly 3.5 million people, or about 27 percent of the state's nearly 12.8 million residents, lived in 48 rural counties of Pennsylvania in 2010. By 2030, this number is projected to increase by 3 percent [12].

The recommendations offered include goals and strategies supportive of Pennsylvania's rural population.

## **A Plan with a Renewed Call for Caring**

***Compassionate, ethical, person-centered, and high quality care across the continuum of the disease, from early diagnosis through the end of life.***

Fellow Pennsylvanians, in sharing their experiences, helped the committee learn more about Alzheimer's disease and related disorders and more about suggestions which helped define what needs to be pursued in endeavors of research; the offering of supportive and clinical services; helping professional and informal caregivers and enhancing communities.

While educational outreach and technical assistance will help greatly to enhance knowledge and skills the committee emphasized several qualitative attributes among systems of care and caregivers.

Hallmarks of care that should be considered as recommendations, goals and strategies include:

- Person-centered care lends priority focus to the needs of the persons when reviewing and possibly revising systems of care. It also incorporates the strengths of medical approaches to care in a more holistic way of caring, which incorporates concern for psychological, social and spiritual as well as the physical. This is critical for ADRD because the concerns of individuals vary considerably depending on their age, the presence of other chronic conditions, family and community support, ethnic, and cultural background, living situation, and many other factors.
- Ethical care recognizes and supports the desires and preferences of the person with ADRD and his or her caregivers. Physicians and other providers of ethical care partner with persons and their families in decision making about issues ranging from treatments, residential choices, driving, and research participation to decisions about hospice and end-of-life care.
- The caring workforce the committee envisions in the Plan would be trained to deliver compassionate, ethical, and person-centered care.

## **A Plan to Chart a New Course of Action**

***Efforts to address ADRD require partnerships***

The committee first recognized the enormous breadth of what is included in a statewide endeavor to help fellow Pennsylvanians living with ADRD. Partnerships are necessary for our communities to become places to age and live well. They serve as a way to strengthen the ongoing need for research in pursuit of a cure and identify priorities for the evolution of care built on existing strengths. The committee also recognized that ADRD is larger than any one sector can address alone. The Plan calls upon the necessary partnerships in services, financing, research and care to maximize the existing and potential resources and foster collaboration to achieve the Plan's recommendations.

The Plan identifies seven recommendations, which provide a definition of the areas of highest priority to be addressed. The goals and strategies are provided to set direction. The Plan is a first step to define a course for Pennsylvania. It is not meant to be a detailed plan of action but a setting of recommended priorities which will be followed by an implementation stage. The strategies presented range from those achievable in short-term to those requiring a more comprehensive time-frame.

The input received from public regional meetings and stakeholders significantly influenced the committee while developing the composition of this Plan. From their responses, experiences and expertise emerged guiding principles that were used during the planning process and applied to all seven of the Plan's recommendations.

### **Planning Process**

Governor Corbett appointed committee members from all regions of the commonwealth and representing diverse stakeholder groups to craft the Pennsylvania ADRD Plan. Legislative members include the majority and minority chairpersons of the Aging and Youth Committee and Public Health and Welfare Committee of the Senate, and majority and minority chairpersons of the Aging and Older Adult Services Committee and Health Committee of the House of Representatives.

The committee began its deliberations in June 2013 in Harrisburg. This was followed by a series of six regional public meetings across the state between July and September, and an additional five meetings of the full committee between October, 2013 and January 2014. The workgroups met via teleconference between July and December, crafting a set of recommendations, goals, and strategies, which were subsequently compiled into an overall framework for the Plan.

The Pennsylvania Alzheimer's Disease Planning Committee at its public meetings included presentations and discussions with national leaders in the field of ADRD and caregiving including:

- Ronald C. Petersen, M.D., Ph.D., is the Cora Kanow Professorship in Alzheimer's Disease Research, and a Mayo Clinic Distinguished Investigator at the Mayo Clinic. He is on the National Advisory Council on Aging, and is the chair of the Advisory Council on Research, Care and Services for the National Alzheimer's Project Act appointed by the Secretary of the Department of Health and Human Services. Dr. Petersen is a recipient of the 2004 MetLife Award for Medical Research in Alzheimer's Disease, the 2004 and the 2005 Potamkin Prize for Research in Pick's, Alzheimer's and Related Disorders of the American Academy of Neurology.
- Katie Maslow MSW is a Scholar-in-Residence at the Institute of Medicine (IOM), with a primary focus on care-related issues for older people with dementia, mental illness and co-existing medical conditions. Before joining the IOM in 2011, Ms. Maslow worked for 15 years for the Alzheimer's Association, where she directed practice, research and policy initiatives to improve the quality, coordination, and outcomes of health care and long-term services for people with Alzheimer's disease and other dementias and their family caregivers. She directed the Association's initiatives on hospital care and managed care

for people with Alzheimer's and other dementias and co-directed its multi-site demonstration project, Chronic Care Networks for Alzheimer's Disease.

- Michael Splaine is currently owner and principal in Splaine Consulting, a small advocacy and government affairs consulting firm based in Washington D.C. Immediately prior to starting this company, Mike was Director of State Government Affairs in the Public Policy Division of the Alzheimer's Association, leading its grassroots network to accomplish state policy priorities, including comprehensive state Alzheimer Plans.
- Steven E. Arnold MD is Professor of Psychiatry and Neurology at the University of Pennsylvania. Dr. Arnold is board certified in both psychiatry and neurology. He is currently Director of the PENN Memory Center of the University of Pennsylvania Health System and Associate Director and Clinical Core Leader of the Alzheimer's Disease Core Center, Director of the Geriatric Psychiatry Section in the Department of Psychiatry, Director of the Cellular and Molecular Neuropathology Program in the Center for Neurobiology and Behavior, and Associate Director of the University of Pennsylvania's Institute on Aging. Dr. Arnold has conducted longstanding research on neurodegenerative disease pathology in relation to cognitive decline in late life and leads a broad clinical and translational research program examining brain and mind aging.

The public regional meetings were designed to understand the needs of Pennsylvanians with ADRD, to find key areas of discussion for Pennsylvanians with ADRD as well as their families and caregivers and to hear ideas for the state to better respond to the growing number of Pennsylvanians with ADRD. Meetings were held in Harrisburg, State College, Scranton, Philadelphia, Clarion and Pittsburgh, The meeting in Clarion was focused on the experience of living with ADRD in the rural communities of Pennsylvania. These comments, summarized in Appendix E, guided the work of the workgroups and ensured that the needs of persons and caregivers remained at the forefront of the committee's deliberations. In addition to the regional meetings, the public was invited to provide comment via letter, email and online survey tool provided through the Pennsylvania chapters of the Alzheimer's Association. In total, over 330 Pennsylvanians provided comment.

### ***The Pennsylvania Alzheimer's Disease State Planning Committee***

#### ***Chair:***

Honorable Brian Duke, Secretary, Pennsylvania Department of Aging

#### ***Committee members representing various constituencies (Appendix C)***

Kelly O'Shea Carney, Ph.D., Executive Director, Center for Excellence in Dementia Care for Phoebe Ministries (Lehigh County), AD Researcher representative

Carrie DeLone M.D., Physician General, Pennsylvania Department of Health (Dauphin County), Department of Health representative

Michael Ellenbogen, Author of "From the Corner Office to Alzheimer's" (Bucks County), Person with AD representative

George Gunn Jr., Reverend, ACTS Retirement – Life Communities Inc. – retired (Montgomery County), Assisted Living representative

Susan Heinle, President and Owner, Visiting Angels (York County), Homecare representative  
Beth Herold, Administrator, Butler County Area Agency on Aging (Butler County),  
Area Agency on Aging representative  
Cynthia Lambert, Vice President for Government and Community Relations, Good Shepherd  
Rehabilitation Network (Lehigh County), Family Member representative  
David Leader, President and CEO, Providence Place Senior Living (Dauphin County), Personal  
Care Home Industry representative  
Robert Marino, Member of the Alzheimer's Association Delaware Valley Chapter Board of  
Directors (Montgomery County), Statewide Alzheimer's Association representative  
Cheryl Martin, Chief of Staff, Office of Long-Term Living (Lebanon County), Department of  
Public Welfare representative  
Robin Mozley, Center Manager, Jeannette Senior Center (Westmoreland County),  
Senior Center representative  
Heidi Owen, Director of Hospice/Oncology Services, Neighborhood Health (Chester County),  
Hospice representative  
Maura Pelinsky, Adult Day Services Director, Saint Mary's East (Erie County), Adult Day  
representative  
Charles F. Reynolds III M.D, UPMC Endowed Professor in Geriatric Psychiatry at the  
University of Pittsburgh School of Medicine and Graduate School of Public Health (Allegheny  
County), Medical Care Provider Community representative  
Jill Fortinsky Schwartz, Owner, Fortune Fabrics and Gosh Yarn It! (Luzerne County), Caregiver  
representative  
Stuart Shapiro, M.D, President and CEO, Pennsylvania Healthcare Association (Montgomery  
County), Nursing Facility representative  
John Trojanowski, M.D. Ph.D., Director, National Institute of Aging Alzheimer's Disease Core  
Center (Philadelphia County), AD researcher representative

***Legislative members:***

*Senate Aging and Youth Committee*

Honorable Bob Mensch, Chair

Honorable Leanna Washington, Minority Chair

*Senate Public Health and Welfare Committee*

Honorable Pat Vance, Chair

Honorable Shirley Kitchen, Minority Chair

*House Aging and Older Adult Services Committee*

Honorable Tim Hennessey, Chair

Honorable Steve Samuelson, Minority Chair

*House Health Committee*

Honorable Matthew Baker, Chair

Honorable Florindo Fabrizio, Minority Chair

## ***Workgroups***

Committee members self-selected to one of three workgroups to address issues related to 1) Prevention and Outreach, 2) Healthcare Delivery and Workforce, and 3) Research and Metrics.

Workgroups met by teleconference call approximately every two weeks to develop recommendations, goals, and strategies relevant to their area of interest.

### Workgroup 1: Prevention and Outreach

To increase awareness of ADRD among the public; study existing resources for addressing the needs of families and persons with ADRD; better inform, equip and educate the public and service/ healthcare providers about ADRD; recommendations to assist unpaid caregivers; promote activities that would maintain and improve brain health and cognitive fitness across the life cycle into old age; improve public safety and address safety-related concerns such as driving; recommendations regarding legal protections and legal issues faced by individuals with ADRD; maintaining an ADRD clearinghouse of information; provide technical assistance and consultation to agencies about available resources, programs and services.

Workgroup Liaison: Steven Horner

Workgroup Members:

- Charles F. Reynolds III, M.D., Chair
- Rev. George Gunn Jr.
- Honorable Matthew Baker
- Michael Ellenbogen
- Honorable Shirley Kitchen
- Honorable Steve Samuelson
- Stuart Shapiro, M.D.
- Maura Pelinsky

### Workgroup 2: Healthcare Delivery and Workforce

To encourage increased detection and diagnosis; improve the individual health care received; expand the capacity of the healthcare system to meet the growing number and needs of those with ADRD; increase the number of service and health care professionals that will be necessary to treat the growing aging and ADRD populations; develop a strategy to mobilize the commonwealth's response to the anticipated increase in incidence of ADRD in PA; improve services provided in the home and community based setting and decrease the need for institutional care; improve access to long-term services and supports.

Workgroup Liaison: Paul McCarty

Workgroup Members:

- Heidi Owen, Chair
- Sue Heinle
- Beth Herold
- Cynthia Lambert
- David Leader
- Cheryl Martin

- Robin Mozley
- Jill Schwartz
- Kelly O’Shea Carney, Ph.D.
- Honorable Leanna Washington
- Honorable Pat Vance

Workgroup 3: Research and Metrics

To improve the quality of information, develop a collaborative to share research results and information; data and service/health systems that serve people with ADRD; examine the needs and research the trends of PA’s ADRD population; recommendations to increase research; to provide cost-effective approaches; recommendations for improved data collection and repository method; analyzing data and ADRD implication on public health; recommendations to improve how government evaluates and adopts policies and to assist people with ADRD and their families.

Workgroup Liaison: Rebekah Ludwick

Workgroup Members:

- Carrie DeLone M.D., Chair
- Robert Marino
- Honorable Bob Mensch
- Honorable Brian Duke
- Honorable Florindo Fabrizio
- John Trojanowski, M.D. Ph.D.
- Honorable Tim Hennessey

## V. Recommendations

The committee developed a series of seven overall recommendations that were designed to mobilize the commonwealth's response to the anticipated increase in the prevalence of ADRD in Pennsylvania.

These recommendations are listed below, not in priority order, but should be reviewed as a series recognizing the breadth of ADRD and the span of need from making the public more aware to efforts focused on risk reduction, cures, and care. All of the recommendations are considered important by the committee.

These recommendations are the culmination of public responses, stakeholder engagement, and expertise of committee members and advisors. These recommendations were developed with the consideration of economic realities and the urgency of ADRD in Pennsylvania. The committee felt strongly that additional resources are needed to address the ADRD epidemic in Pennsylvania, but also places equal emphasis on public and private partnerships to implement the Plan.

Recommendation 1 - Improve awareness, knowledge, and sense of urgency about medical, social, and financial implications of ADRD across the commonwealth.

Recommendation 2 - Due to the magnitude of the ADRD epidemic, identify and, where possible, expand financial resources to implement this plan through federal, state, foundation, private, and other innovative funding mechanisms and partnerships.

Recommendation 3 - Promote brain health and cognitive fitness across the life cycle from birth onward.

Recommendation 4 - Provide a comprehensive continuum of ethical care and support that responds to social and cultural diversity, with services and supports ranging from early detection and diagnosis through end of life care.

Recommendation 5 - Enhance support for family and non-professional caregivers and those living with ADRD.

Recommendation 6 - Build and retain a competent, knowledgeable, ethical, and caring workforce.

Recommendation 7 - Promote and support novel and ongoing research to find better and effective cures, treatments, and preventive strategies for ADRD.

## VI. Action Plan: Recommendations, Goals, and Strategies

### **Recommendation 1:**

**Improve awareness, knowledge, and sense of urgency about medical, social, and financial implications of Alzheimer’s disease and related disorders (ARD) across the commonwealth.**

#### **Background and rationale:**

Alzheimer's disease is among the most feared diseases in the United States, yet most people know little or nothing about it [27]. This lack of awareness and understanding results in stigmatization of those affected as well as their caregivers, and prevents people from getting a diagnosis, planning for the future, and receiving help until it is too late.

While there is an abundance of information regarding ARD in various locations, nonetheless, accessing, understanding and using the information can be difficult. However, increasing understanding among the public and policy makers may serve to engage all parties in addressing the challenges faced by individuals, caregivers and the society as a whole.

A relatively recent approach to enabling people with ARD to live as independently and optimally as possible is the development of dementia friendly communities [28]. These communities provide a high quality of life for those with ARD, in part by raising awareness and knowledge among all community members, including those working in any business that deals with the public (e.g. banks, restaurants), as well as emergency responders. Through these efforts, people with ARD are provided safe environments and protected against abuse and financial exploitation.

#### **Goal 1A**

Determine baseline and outcome data regarding the prevalence and demographic characteristics of Pennsylvanians with ARD, including age of onset, comorbid conditions, prevalence of risk factors, use of medications, and health inequities and disparities.

#### **Strategies to achieve this goal:**

- Partner with health survey experts to design and conduct the survey.
- Implement the Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System’s (BRFSS) Cognitive Impairment & Caregiver modules. Use data to enhance awareness and action in statewide public health programming for ARD.

### **Goal 1B**

Determine the economic impact of ADRD on Pennsylvania.

#### **Strategies to achieve this goal:**

- Conduct an economic analysis of the negative impact of ADRD on the commonwealth, including the cost to Medicaid and other state programs, as well as predictions of future economic impact.
- Conduct an economic analysis on the potential economic benefits that accrue to PA because of research and technology development and increased employment in the healthcare industry related to ADRD; as well as the potential for increased economic benefits from an expansion of research, development, and care services.

### **Goal 1C**

Reduce the stigma associated with ADRD by raising awareness and knowledge among the public with key message that living well with ADRD is an attainable goal.

#### **Strategies to achieve this goal:**

- Develop a communications strategy to increase public understanding of ADRD and provide information about how to live well with ADRD.
- Allocate sufficient revenues to have a meaningful advertising campaign to accomplish the primary goal of educating the public about ADRD and available resources for living well with ADRD.

### **Goal 1D**

Raise ADRD awareness and knowledge among health-care providers, public health professionals, and aging services providers.

#### **Strategies to achieve this goal:**

- Disseminate information to primary care providers about the Medicare wellness visit.
- Explore revisions to continuing education curricula.
- Explore partnerships with organizations to develop and provide training.
- Encourage the inclusion of ADRD training in medical school curricula and in the curricula of other health professions.
- Encourage inclusion of ADRD-related content in publicly funded and regulated provider education among healthcare providers, public health professionals, and aging services providers.

### **Goal 1E**

Improve information sharing regarding treatment and risk reduction options (including the goals discussed in recommendation 3) for ADRD with residents of Pennsylvania to improve quality of life and patient outcomes.

#### **Strategies to achieve this goal:**

- Ensure that a statewide comprehensive central clearinghouse on ADRD information for family members and caregivers is developed and maintained.
- Develop improved modalities of information-sharing available to all Pennsylvanians, providers, public health workers, and agencies, including evidence-based practices.
- Achieve better alignment, consistency, and availability of information about Alzheimer's disease and related disorders across the Pennsylvania Departments of Aging, Health, and Public Welfare and other state and federal agencies.

### **Goal 1F**

Promote and support the development of dementia friendly communities to empower individuals with ADRD and their caregivers and to combat stigma.

#### **Strategies to achieve this goal:**

- Examine other successful models of dementia friendly communities.
- Develop and disseminate a statewide standard education and public awareness campaign about dementia friendly communities.
- Promote voluntary 911 registries for individuals with ADRD.
- Promote possibility of sharing Pennsylvania residents' data from national and other databases with programs related to disaster preparedness.
- Promote training for police, fire fighters, emergency personnel, and postal workers how to interact with individuals with ADRD.

### **Goal 1G**

Improve the safety of individuals with ADRD in communities across the commonwealth.

#### **Strategies to achieve this goal:**

- Inventory, implement, and/or develop training for police, fire fighters, emergency personnel, and postal workers to help them identify and interact with individuals affected by ADRD.
- Work with law enforcement to broaden awareness and promote the existing Missing Endangered Persons Alert System (MEPAS) in Pennsylvania.
- Increase awareness and usage of services and devices that improve safety for persons who wander, including GPS and web-based home monitoring services.

- Integrate strategies within current disaster preparedness plans that address the safety of vulnerable populations.
- Explore tools to identify those no longer capable of driving and strategies for implementing these tools.
- Partner with law enforcement on the promotion of home safety and firearm safety.

### **Goal 1H**

Protect individuals with ADRD from abuse and financial exploitation using guidance from key federal and state agencies.

#### **Strategies to achieve this goal:**

- Use guidance from key federal and state agencies.
- Identify and potentially form partnerships with for-profit and non-profit organizations that are working in the areas of neglect, abuse, and financial exploitation.
- Communicate with financial institutions and other organizations regarding best practices to identify signs of financial exploitation.
- Promote public awareness to identify neglect, abuse, and financial exploitation.

### **Goal II**

Convene annual Pennsylvania Alzheimer's Plan Summit meetings to evaluate progress of the Plan, strengthen partnerships, build community support for the Plan, recognize excellence, and identify next steps.

#### **Strategies to achieve this goal:**

- Partner with experts in implementation and evaluation science to formulate an evaluation plan.
- Recognize excellence in various domains (e.g. improving safety; combatting abuse, neglect, and financial exploitation; developing dementia friendly communities; promoting brain health and cognitive fitness; improving care coordination, etc.) at the annual meetings to encourage further deployment of like models throughout the commonwealth.
- Conduct ongoing updates of baseline information which will be utilized and analyzed for long-term planning, including a process to document any cost savings through implementation of the Plan strategies at each summit meeting.

**Recommendation 2:**

**Due to the magnitude of the ADRD epidemic, identify and where possible expand financial resources to implement this plan through federal, state, foundation, private, and other innovative funding mechanisms and partnerships.**

**Background and rationale:**

As the population ages, the number of Pennsylvanians with ADRD will continue to grow. This growth will pose a significant challenge related to the demand for care to both public and private funders as well as to the care delivery system. While additional investments from the federal government have been announced, there remains a gap between the funding for ADRD research compared to that of major causes of morbidity and mortality such as cancer and heart disease. Given the limited resources currently available to states such as Pennsylvania, there is an urgent need to identify innovative, non-traditional funding sources for ADRD research and care.

**Goal 2A**

Review and maximize utilization of existing financial resources to ensure that individuals with ADRD receive care in the most appropriate and cost-efficient setting.

**Goal 2B**

Develop and/or promote programs to encourage research and technology development in the area of ADRD.

**Strategies to achieve this goal:**

- Seek grant money to support ADRD research and technology.
- Create an environment that invites research and technology development.

**Goal 2C**

Identify and implement innovative funding mechanisms to support research aimed at finding cures, treatments, and prevention strategies for ADRD.

**Strategies to achieve this goal:**

- Approach private foundations for grant support to sponsor this type of research.
- Pursue public-private partnerships with corporate entities to sponsor this type of research.
- Pursue supplemental funding to federally funded research and practice grants.

**Goal 2D**

Develop collaborative public-private investments in awareness campaigns, education, services, and caregiver support.

**Strategies to achieve this goal:**

- Partner with foundations and community service entities to co-sponsor these initiatives.
- Identify what is available in the private sector with regard to awareness campaigns, education, services, and research to reduce duplication of services.
- Identify and engage the support of non-traditional partners (such as utility companies, insurance providers, health plans, sports teams, billboard companies, banks, and agricultural extension offices) in disseminating educational materials and resources that foster public awareness of ADRD and services available.

**Goal 2E**

Advocate for increased federal support for ADRD research.

**Recommendation 3:  
Promote brain health and cognitive fitness across the life cycle from birth  
onward.**

**Background and rationale:**

Research suggests that about half of ADRD risk is linked to seven modifiable lifestyle factors: diabetes, hypertension, obesity, smoking, depression, education, and physical activity [29]. Moreover, epidemiologic studies in Europe indicate that the prevalence of ADRD is on the decline, possibly as a result of improvements in overall health, particularly heart health [30, 31]. Thus, despite the lack of direct proof that a healthy lifestyle lowers the risk of ADRD, there is a public health need to educate residents about behavioral strategies that promote heart and brain health.

**Goal 3A**

Potentially delay the onset of ADRD by promoting brain health and cognitive fitness.

**Strategies to achieve this goal:**

- Inventory what is known about promoting and maintaining a healthy brain.
- Develop a communications strategy to increase public understanding of cognitive health and the connection between improved heart health and improved brain health, as well as the link between depression and cognitive health. Messages should be multipronged, science based, and targeted to all Pennsylvanians, including underserved and vulnerable populations.
- Promote self-management tools to encourage healthy lifestyle choices, (e.g. healthy diets, increased physical activity, weight management, sleep health and smoking cessation).

**Goal 3B**

Build capacity to promote brain health through partnerships among government agencies, patient advocacy organizations, health care systems, academic institutions, and payers (e.g. insurance companies and Medicare).

**Strategies to achieve this goal:**

- Promote strategic partnerships among associations, government agencies, insurers, other payers, private industry, public organizations, and elected officials to support and advance research and policy relevant to cognitive health.
- Identify and implement public policy changes at the state and local levels that would encourage and promote brain health (e.g. pilot nutrition and physical activity programs).
- Strengthen and maintain community infrastructure that reinforces brain-healthy behaviors.

**Recommendation 4:**

**Provide a comprehensive continuum of ethical care and support that responds to social and cultural diversity, with services and supports ranging from early detection and diagnosis through end-of-life care.**

**Background and rationale:**

Providing high quality, ethical, and person-centered care for individuals with ADRD requires a multi-modal approach across the continuum of the disease, with smooth transitions and coordination between care settings. Person-centered care focuses on the person rather than the disease. This is critical for ADRD because the concerns of persons vary considerably depending on their age, the presence of other chronic conditions, family and community support, ethnic and cultural background, living situation, and many other factors. Ethical care recognizes and supports the desires and preferences of the person with ADRD and his or her caregivers. Physicians and other providers of ethical care partner with persons and their families in decision making about issues ranging from treatments, residential choices, driving, and research participation to decisions about palliative care. The caring workforce envisioned in the Plan would be trained to deliver compassionate, ethical, and person-centered care.

**Goal 4A**

Assess the current strengths, gaps, and barriers within the continuum of care of each Pennsylvania county in its ability to support all individuals with ADRD and their caregivers.

**Strategies to achieve this goal:**

- Conduct a needs assessment to identify strengths, gaps, and barriers to the provision of appropriate care for individuals with ADRD and disseminate results.
- Determine numbers and geographic distribution of various related specialists supporting individuals with ADRD.
- Promote partnerships with not-for-profit hospitals on community assessments conducted every three years to identify gaps and incorporate information on caring for people with ADRD.
- Incorporate assessment of ADRD needs into the Area Agencies on Aging planning process.
- Encourage uniformity and collaboration in ADRD care guidelines across regulating bodies.

#### **Goal 4B**

Develop a plan to address the identified gaps in the continuum of care, including, but not limited to, adult day services, palliative care, end-of-life care, transportation, private duty, respite care, and other home and community-based services.

##### **Strategies to achieve this goal:**

- Identify regulatory, legal, and reimbursement barriers to the provision of appropriate care for individuals with ADRD.
- Encourage the appropriate use of palliative care to enable individuals to age in place.
- Promote the credentialing of care managers to serve individuals with ADRD and their caregivers.

#### **Goal 4C**

Expand availability of and access to care management services in order to coordinate services for individuals with ADRD living in settings across the continuum of care.

##### **Strategies to achieve this goal:**

- Promote utilization of best practices for ADRD care coordination.
- Develop referral processes to encourage use of private geriatric care management for individuals whose means exceed eligibility levels for public case management services.
- Research reimbursement availability for care coordination activities including team-based approaches within primary care.
- Educate health care providers about the benefits of care coordination.
- Extend the best practices infrastructure currently used by PACE/PACENET to provide information and assistance regarding all programs and services.

#### **Goal 4D**

Increase the early detection and diagnosis of ADRD by promoting the assessment of cognitive health and depression.

##### **Strategies to achieve this goal:**

- Recommend cognitive health and depression assessments in annual routine physical exams.
- Encourage incorporation of this recommendation into guidelines for medical homes, accountable care organizations and other current and future models of care.

**Goal 4E**

Improve quality of life, safety and cost of care by maintaining individuals with ADRD in the most appropriate and cost-effective settings.

**Strategies to achieve this goal:**

- Collaborate with community organizations to develop and test new models of community-based care.
- Encourage collaborative efforts to bridge science and service to support independence and quality of life in Pennsylvania's residents with ADRD.

**Goal 4F**

Promote innovation in service systems and funding mechanisms related to the care of individuals with ADRD, including underserved populations and those in rural communities of the commonwealth, which improve quality of care and support, enhance quality of life, create efficiencies, and reduce costs.

**Strategies to achieve this goal:**

- Support the development of innovative programs to improve the care of persons with ADRD.
- Encourage state-funded grant programs to demonstrate the effectiveness of innovative approaches to the care of persons with ADRD.
- Expand the use of telemedicine and telepsychiatry where it provides an advantage.
- Encourage implementation of electronic health records through the commonwealth.
- Encourage community specific best practice care models.
- Complete prescription utilization review and intervention for PACE enrollees with ADRD.
- Create and implement an online continuing medical education (CME) accredited program to educate physicians and in their offices to identify and treat ADRD.

**Recommendation 5:****Enhance support for family and non-professional caregivers and those living with ADRD.****Background and rationale:**

The number one issue in the public comments was the need for improved caregiver support. According to the Alzheimer's Association [1], 667,000 caregivers in Pennsylvania provided some 750 million hours of unpaid care to people living with ADRD. The value of this care has been estimated at over \$9 billion. What is more difficult to estimate is the impact of caregiving on the caregiver. Many studies have reported a higher level of emotional stress among those who provide care for persons with ADRD than for other chronic diseases of the elderly. The demands of caregiving also come with significant financial costs in terms of lost productivity, missed career opportunities, lost jobs or early retirement, and out-of-pocket costs. The result of this added emotional and financial stress can place a significant strain on families, marriages, and the caregiver's overall health. In Pennsylvania, higher health care costs of caregivers have been estimated at \$447 million [1].

**Goal 5A**

Conduct an assessment of caregiver needs, including, but not limited to, legal and financial guidance, respite care, psychological counseling, and stress management.

**Strategies to achieve this goal:**

- Partner with survey experts to design and conduct such surveys.
- Take advantage of existing databases that assess these needs.

**Goal 5B**

Provide resources and support that will better enable informal (i.e. non- professional) caregivers to care for their loved ones and themselves.

**Strategies to achieve this goal:**

- Disseminate information about currently available web and paper-based tools for family and long-distance caregivers.
- Partner with organizations to develop materials that are understandable and appropriate across varied population groups.
- Inventory and make available a listing of caregiver support groups.
- Encourage the establishment of additional caregiver support groups in geographical areas currently lacking such groups.
- Encourage the use of Health Insurance Portability and Accountability Act (HIPAA) compliant, web-based health-tracking tools that facilitate communication between informal caregivers and healthcare providers.

- Explore legislation to provide financial support to caregivers.

### **Goal 5C**

Address the unique needs of those living with ADRD.

#### **Strategies to achieve this goal:**

- Identify and expand, if necessary, psycho-social counseling services for individuals living with ADRD.
- Identify and expand, if necessary, services for individuals living alone with ADRD.

### **Goal 5D**

Provide training and education for non-professional caregivers and those living with ADRD.

#### **Strategies to achieve this goal:**

- Identify and/or develop culturally and linguistically appropriate educational and training tools for families and caregivers, with the goal of ensuring that all understand ADRD implications.
- Disseminate these tools throughout the community.
- Utilize and strengthen linkages between medical care team and informal caregivers.

## **Recommendation 6:**

### **Build and retain a competent, knowledgeable, ethical, and caring workforce.**

#### **Background and rationale:**

Quality medical care for people living with ADRD may come from a range of providers who may not have the knowledge or tools necessary to provide appropriate care. Younger onset patients may have particular difficulty getting an accurate diagnosis due to lack of knowledge about early-onset disease among the medical community. Older persons face a different set of problems in that they often have multiple interacting chronic conditions, take multiple medications, and may be in transition between in-patient, out-patient, and long-term care settings. Regardless of the presentation, people living with ADRD deserve care that focuses on their individual needs rather than a disease-focused approach.

Care providers must also be prepared to deal with a number of ethical issues that may arise. For example, persons and family members may seek guidance from care providers regarding whether or not to undergo pre-symptomatic diagnosis and their capacity for decision making about treatments, residential choices, driving, research participation, hospice, and end-of-life care.

Currently in Pennsylvania, there is a shortage of appropriately trained primary and other health care providers to serve the growing number of individuals with ADRD. This problem is especially acute in rural areas and among persons with lower income and those with special needs.

#### **Goal 6A**

Educate physical and behavioral health care professionals at all levels of care about the unique needs of persons with ADRD.

#### **Strategies to achieve this goal:**

- Establish core curricula for ADRD training in Pennsylvania, for health care professionals at all levels drawing on tools and training requirements that already exist.
- Collaborate with state agencies, licensing boards and networks to incorporate ADRD training in licensing regulations across the continuum of care (e.g. AAAs, Pennsylvania Departments of Aging, Health and Public Welfare).
- Engage existing organizations related to health care, behavioral health services, long-term care, and community-based services to assist with provider education.

**Goal 6B**

Encourage professionals to pursue and remain in careers in ADRD care.

**Strategies to achieve this goal:**

- Promote innovative practices to encourage recruitment of competent and ethical individuals to meet the needs of the diverse growing population of persons with ADRD.
- Promote innovative practices to encourage retention of a competent and ethical workforce for the care of individuals with ADRD in Pennsylvania.
- Advocate loan forgiveness for individuals pursuing advanced professional training in physical and behavioral health specialties related to ADRD.
- Promote career development to encourage advancement in employment.
- Research available grant opportunities for workforce investment, vocational training, and community college certification programs to recruit and appropriately train a workforce focused on the care of persons with ADRD.

**Recommendation 7:****Promote and support novel and ongoing research to find better and effective cures, treatments, and prevention strategies for ADRD.****Background and rationale:**

Identifying new and effective treatments, cures, and prevention strategies for ADRD was recognized as a critical need by NAPA, as well as other plans put forward to address the ADRD epidemic [32]. While most ADRD research in the United States is funded by the National Institute on Aging and the pharmaceutical industry, collaborations are clearly needed that incorporate a broader group of stakeholders, including health care providers, payers, advocacy organizations, foundations, regulators, and especially the public. States such as Pennsylvania can play an important role in research by raising awareness among the public and care providers about the importance of research and by partnering with others to promote clinical trials. The impact of developing improved therapies that could slow the progression of ADRD could not only decrease disease burden but could also have a positive impact on business development, job creation, research development, and Medicare/Medicaid cost savings.

**Goal 7A**

Promote participation in clinical trials, ensuring inclusion of underserved and rural populations.

**Strategies to achieve this goal:**

- Develop public and provider awareness information regarding clinical trials, to be distributed directly to primary care providers, patients, and families in a variety of modalities.
- Develop and use existing education and FAQs for providers to distribute to patients and families at the time of diagnosis regarding clinical trials registries and qualifying requirements to engage in study protocols.
- Increase awareness of web-based clinical trial finder sites.
- Explore approaches that would enable the expansion of clinical trials to satellite facilities, including training of personnel, telemedicine, and remote video conferencing approaches.

**Goal 7B**

Promote Pennsylvania as a magnet for clinical research by developing a network of hospital and other health care providers with clinical research capability across the commonwealth.

**Goal 7C**

Cultivate collaborative efforts of the research, clinical, pharmaceutical, regulatory, and payer communities to identify barriers and solutions at each stage of treatment development with the goal of producing novel methods to prevent and treat ADRD.

**Goal 7D**

Provide incentives for biomedical technology companies working in the ADRD field to remain in or relocate to Pennsylvania.

**Strategies to achieve this goal:**

- Draw on the experience of other states in this domain.
- Promote and/or support legislation and/or incentives that would make Pennsylvania an attractive location for biomedical technology companies.

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<p><b>Executive Order</b>  <b>Commonwealth of Pennsylvania</b>  <b>Governor's Office</b></p>	
<p><b>Subject:</b>  <b>The Pennsylvania Alzheimer's Disease Planning Committee</b></p>	<p><b>Number:</b>  <b>2013-01 As Amended</b></p>
<p style="text-align: center;"></p> <p><b>By Direction of: Tom Corbett, Governor</b></p>	<p><b>Date: March 20, 2013</b></p>

WHEREAS, creation of a plan to address the epidemic of Alzheimer's disease and other related brain disorders in our Commonwealth is a major concern of this administration; and

WHEREAS, the Pennsylvania Department of Aging was created in 1978 by *Act 70* as a cabinet-level state agency whose jurisdiction, powers and duties specifically concern and are directed to advancing the well-being of Pennsylvania's older citizens; and

WHEREAS, *Act 70* authorizes the Department of Aging to "develop and periodically update a comprehensive plan for coordinating all major Commonwealth services, programs and activities which are directed towards persons with chronic physical or mental impairments which necessitate long-term care"; and

WHEREAS, *Act 70* further authorizes the Department of Aging to: "maintain a clearinghouse of information related to the interests of older persons and provide technical assistance and consultation to all agencies, both public and private with respect to programs and services for older persons"; and

WHEREAS, *Act 70* directs the Department of Aging to undertake "special advocacy efforts to promote greater awareness of, and more effective response to, the problems of persons with Alzheimer's disease and other related brain disorders"; and

WHEREAS, Alzheimer's disease currently affects one in twelve Pennsylvania families; and

WHEREAS, the interests of this Commonwealth would be best served by establishing a planning committee within the Department of Aging to develop and recommend to the Governor and the Department a State Alzheimer's Plan that will serve as a comprehensive approach to addressing the growing Alzheimer's disease crisis.

NOW, THEREFORE, I, Tom Corbett, Governor of the Commonwealth of Pennsylvania, by virtue of the authority vested in me by the Constitution of the Commonwealth of Pennsylvania and other laws, do hereby establish the Pennsylvania Alzheimer's Disease Planning Committee (hereinafter referred to as "Committee").

- 1. Purpose.** The purpose of the Committee shall be, working with the Department of Aging and other state agencies, to consult with residential and community care providers, professional and family caregivers and persons affected by Alzheimer's disease and related disorders to create for the consideration of the Governor and the Department a comprehensive plan for a thoughtful, integrated and cost-effective approach to addressing the needs of persons with Alzheimer's disease and other related brain disorders.
- 2. Responsibilities.** The responsibilities of the Committee shall be to:
  - a. Examine the needs and research the trends in the Pennsylvania's Alzheimer's population;
  - b. Study existing resources for addressing the needs of persons with Alzheimer's disease, and their families and caregivers;
  - c. Develop for the consideration of the Governor and the Department of Aging a strategy to mobilize the Commonwealth's response to the anticipated increase in incidence of Alzheimer's disease in Pennsylvania; and
  - d. Make recommendations to the Governor.
- 3. Composition.** The Secretary of Aging or a designee shall serve as the Chairperson and shall provide administrative support and other resources determined by the Secretary of Aging necessary to fulfill the requirements of this Executive Order. Other members of the Committee shall consist of:
  - a. The majority and minority chairpersons of the Aging and Youth Committee and the Public Health and Welfare Committee of the Senate or their designees;
  - b. The majority and minority chairpersons of the Aging and Older Adult Services Committee and the Health Committee of the House of Representatives or their designees; and
  - c. Certain other members appointed by the Governor who shall consist of: one person affected by Alzheimer's disease, one caregiver of a person with Alzheimer's disease; one family member of a person with Alzheimer's disease; one representative of the nursing home industry; one representative of the assisted living industry; one representative of the personal care home industry; one representative of the adult day-care services industry; one representative of the home care industry; one representative of the medical care provider community; one Alzheimer's disease researcher; one representative of a statewide Alzheimer's association; one representative each of the Pennsylvania Departments of Health and of Public Welfare; one representative of the hospice industry; one representative of a senior center; and one representative of the area agencies on aging.
- 4. Terms of Membership.**
  - a. Members shall be appointed for terms of one year. All members appointed by the Governor shall serve at the pleasure of the Governor;
  - b. Committee vacancies that may occur shall be appointed in accordance with Section 3 of this Executive Order. Successors shall be appointed for the remainder of the original one year term; and

- c. A member who is absent from two consecutive meetings of the Committee, without excuse, shall forfeit membership on the Committee, and a replacement member shall be appointed in accordance with Section 3 of this Executive Order.
- 5. **Compensation.** Members of the Committee shall receive no compensation for their service.
- 6. **Effective Date.** This Executive Order shall take effect immediately.
- 7. **Termination Date.** This Executive Order shall expire on February 7, 2014.

## Appendix B

### **Abbreviations and Acronyms**

AAAs – Area Agencies on Aging. There are 52 agencies serving all 67 counties in Pennsylvania to provide information, support, resources and services.

AD – Alzheimer’s disease, the most common type of late-life dementia.

ADRC- Alzheimer’s Disease Research Center

ADRD – Alzheimer's disease and related disorders. Throughout this document, this term is used rather than “AD” to draw attention to the fact that there are many different disorders that cause dementia. DLB – Dementia with Lewy Bodies; a form of dementia in which protein clumps called Lewy bodies are found in the brain. People with DLB may have hallucinations and motor symptoms similar to those seen in Parkinson’s disease.

FTD – Frontotemporal dementia; the most common of the FTLD group of disorders. People with FTD often experience changes in behavior, language, and social skills.

FTLD – Frontotemporal lobar degeneration; a group of disorders that together comprise the second most common cause of dementia in those under age 65. FTD is the most prevalent

PD – Parkinson disease; the second most common neurodegenerative disease after AD, affecting over one million Americans. The classic signs include tremors, muscle rigidity, and slow movement. In late stages, about 20-40 percent of people with PD develop dementia.

YOAD/EOAD – Early onset AD; refers to dementia that occurs in younger adults, some as young as their 30s, but more often in their 40s and 50s.

## Appendix C

### **Pennsylvania Alzheimer's Disease Planning Committee Biographies**

#### **Representative Matt Baker**

Rep. Matt Baker is serving his 11<sup>th</sup> term, representing all of Tioga County and western Bradford County. Prior to his election in 1992, he served as a district legislative aide for 12 years handling constituent services. Previously, he worked in a Wellsboro law firm for 12 years, serving people with disabilities. Rep. Baker is the majority chairman of the House Health Committee; a member of the Human Services Committee and Rules Committee, the Rural Caucus, Tax Reform Caucus and the Firefighters and Emergency Services Caucus. Rep. Baker is on the Board of Governors of the State System of Higher Education, the Capitol Preservation Committee and the Marcellus Institute Resource Council. He authored the Pipeline Safety Act and was a lead supporter for passage of Act 13 of 2012. He helped create the Yellow Dot Program and the Emergency Contact Information Program. Rep. Baker was prime sponsor of Act 112 of 2011, known as the Pennsylvania Caregiver Support Act. The law increased reimbursements and expanded the scope of the former Family Caregiver Support Program. Rep. Baker has received many civic and humanitarian awards. He also attained a 20-year record of perfect attendance at every House floor session since becoming a state legislator. He has a Bachelor of Science degree as an honors scholar from Elmira College and was awarded an honorary Doctor of Public Service degree from Mansfield University.

#### **Kelly O'Shea Carney, PhD, CMC**

Dr. Kelly Carney is the Executive Director of the Dementia Center for Excellence for Phoebe Ministries, a premier provider of services to older adults in northeastern Pennsylvania. She is a licensed psychologist with a specialty in geriatrics. At Phoebe Ministries, Dr. Carney oversees development of comprehensive services provided to individuals with dementia and their caregivers. A subject matter expert in assessment and management of challenging behaviors associated with dementia, Dr. Carney has provided training at the state and national level to professional caregivers. She is a frequent speaker on eldercare topics to professional groups including: the American Psychological Association, the National Association of Professional Geriatric Care Managers, the Pennsylvania Bar Institute, Pennsylvania Community Providers Association, and the Pennsylvania Long Term Living Training Institute. Dr. Carney earned her bachelor's degree summa cum laude in psychology from St. Mary's College in Notre Dame, Ind., and her master's degree and PhD in counseling psychology with an emphasis in geropsychology from Southern Illinois University in Carbondale, Ill. She obtained her certification as a care manager from the National Academy of Certified Care Managers in Colchester, Conn.

#### **Brian M. Duke, MHA, MBE** *Committee Chair*

Brian Duke was nominated by Governor Tom Corbett to be the Secretary of Aging on February 3, 2011, and confirmed by the Pennsylvania Senate on May 3, 2011. At that time he was Director of the Bucks County Area Agency on Aging. Previously he served as Executive Director of the

New Jersey Foundation for Aging. Mr. Duke had served as a consultant with the U.S. Administration on Aging and the AARP Foundation to develop statewide care-giving coalitions in 12 states. He also co-chaired the Caring Community, a coalition of more than 100 organizations convened by WHYY, the public broadcasting station in the Philadelphia region. He was a consultant with the Family Caregiver: Outreach and Assistance in Our Communities Project with the Pennsylvania State University, as Director of Geriatric Program Initiatives with the Institute on Aging of the University of Pennsylvania Health System; and Secretary of the Board of the Pennsylvania Association of Area Agencies on Aging. Mr. Duke holds a BS in Business Administration from the University of Scranton, an MHA (Health Administration) from George Washington University and an MBE (Bioethics) from the University of Pennsylvania. He is an Associate Fellow of the Institute on Aging of the University of Pennsylvania.

### **Michael Ellenbogen**

Michael Ellenbogen was diagnosed with younger-onset Alzheimer's disease in 2008 at the age of 49. His position at the time was network operations manager for a Fortune 500 company. Difficulty with work-related tasks such as organization, processing, concentration and communication eventually led to early retirement. Since the diagnosis, he has become a world renowned 'Alzheimer's Advocate' through social media, links to "4,000 of the brightest minds that have anything to do with dementia," speaking engagements, media interviews and fundraisers for research and discovery of treatment. Mr. Ellenbogen has written for blogs, newspapers and websites and shared his perspective as guest speaker on teleconferences for caregivers and others with dementia. Michael wrote about his journey with the disease in his latest book entitled "From the Corner Office to Alzheimer's." A regular participant at the Advisory Council on Alzheimer's Research, Care and Services quarterly meetings, he was featured in the Alzheimer's Disease International's 2012 World Alzheimer's Report addressing the stigma of the disease. He lives in Jamison, Pennsylvania, with wife, Shari. They have a daughter, Jamie.

### **Carrie DeLone, MD**

Carrie DeLone, M.D. was nominated by Governor Tom Corbett in April of 2013 for the position of Physician General for the Commonwealth of Pennsylvania. Her role will be to advise the Governor and the Secretary of Health on health matters and policy. Her insights into prevention of injury and disease, safe delivery of quality healthcare, and the promotion of healthy lifestyles will support the continuing efforts of the Pennsylvania Department of Health. For the last nine years, Dr. DeLone has been the physician advisor to the medical staff of Holy Spirit Hospital in Camp Hill. This role included educating physicians regarding federal and state regulations, developing quality improvement strategies, and interacting with insurers. Dr. DeLone is committed to increasing access to medical care, especially in underserved and rural areas, modernizing the present system, with strategies to decrease prescription drug abuse, and health issues such as childhood obesity and immunization. After receiving a BS in biology from Villanova University and a MS in physiology from Georgetown University, Dr. DeLone attended Temple University School of Medicine and completed training at the Upstate Medical Center in Syracuse, N.Y. She has been board certified in internal medicine since 1985.

### **Representative Florindo ‘Flo’ Fabrizio**

Representative Florindo J. “Flo” Fabrizio, a lifelong resident of Erie, was elected to the Pennsylvania House of Representatives in 2002, and is now serving in his sixth term. He is currently the Democratic Chair of the House Health Committee. Representative Fabrizio is also a member of the Policy Committee and serves as Deputy Whip of the Democratic Caucus. In past sessions, he was a member of the Aging and Older Adult Services, Finance, Insurance, State Government and Gaming Oversight Committees. In addition, he chairs the Joint State Government Commission. Having graduated from Strong Vincent High School in Erie, Representative Fabrizio earned a Bachelor of Arts degree from the Pennsylvania State University and a Master’s degree from Edinboro University.

### **Reverend George R. Gunn, Jr.**

Following a successful 30-year career in marketing and advertising for Fortune 500 companies, Rev. George R. Gunn served from 1995-2005 as Chief Executive Officer, Board member and Chaplain of ACTS Retirement-Life Communities. ACTS provides residential housing and long-term care residences in several states to nearly 8,500 seniors. A partial list of Rev. Gunn’s community and charitable affiliations includes: the Pennsylvania Council on Aging, 1999 to the present; received The Secretary’s Award 2011, and the Paul P. Haas Lifetime Achievement Award from PANPHA 2005; Bible Theological Seminary; Philmont Christian Academy; The Salvation Army; Philadelphia Council, Boy Scouts of America; the Charles Morris Price School of Advertising & Journalism, Distinguished Alumnus 1979; the Philadelphia Presbyterian Home at 58<sup>th</sup> St.; Young life Campaign; The Greater Philadelphia Billy Graham Crusade 1992; The Union League of Philadelphia and many more. Rev. Gunn, a United States Navy veteran, holds a Bachelor of Science degree in Marketing, a Master's degree in Business Administration from Temple University, and a Master of Divinity degree from Princeton Theological Seminary.

### **Susan Bailey Heinle, RN., BSN**

Susan Heinle is a nursing leader with 31 years of experience in home care, hospice, and private duty businesses. She owns and is President of Visiting Angels, a non-medical, in-home care service for adults and seniors. From concept, to start-up, to daily operations, Mrs. Heinle has developed a successful for-profit agency serving York and Hanover communities. Visiting Angels lives its mission each day by helping clients to stay at home rather than move to a nursing facility. In this way, Mrs. Heinle’s business choice has dovetailed with the prime movement in aging services for the 21<sup>st</sup> century: aging in place. Before Visiting Angels, she was President of Comfort Care of Holy Spirit, Inc., and for a decade practiced her profession as staff and head nurse, clinical supervisor and Director of Home Health Services at York’s Memorial Hospital. Recognized as a community business leader, she received the 40 Under 40 Award by the Central Pennsylvania Business Journal in 1999; the Pennsylvania’s Best 50 Women in Business Award in 2007; and the 2010 and 2011 Central Penn Parent Healthcare Hero Award. Mrs. Heinle earned a Bachelor of Science in Nursing from York College of Pennsylvania.

## **Representative Tim Hennessey**

A long-time community servant as legislator, dedicated attorney, trial attorney with the Public Defenders office from 1973 to 1992, and lifelong resident of Chester County, Tim Hennessey has represented the 26<sup>th</sup> District since 1993. He serves as the Republican Chairman of the Aging and Older Adult Services Committee. He wants to streamline government services for older Pennsylvanians for clarity and accessibility; and ensure that the Lottery Fund remains solvent for future generations. Chairman Hennessey was prime sponsor of Act 108 of 2012 (House Bill 1720), known as the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (UAGPPJA). The law addresses jurisdictional issues surrounding the guardianship of adults and ensures reciprocity of acknowledgement of guardianship or conservatorship across states. Act 108 is recognized nationally as a significant elder abuse deterrent to the practice of “granny snatching”. Hennessey also serves on the House Local Government Committee. During his tenure he has authored legislation helping local governments tackle urban blight and abandoned property. He is also a strong advocate for property tax relief and improving schools. In addition to committee work, Hennessey chairs the Steel and Irish caucuses. Prior to his election to the House, Tim Hennessey served as chairman of the Rotary Student Exchange Program; he was president of the Birthright of Pottstown and past president of the Alternatives Corporation of Pottstown, a shelter home for abused children. He earned a Bachelor of Science degree from St. Joseph’s University and a Juris Doctor degree in 1972 from Villanova University School of Law.

## **Beth Herold**

For the past 25 years, Beth Herold has served the needs of the aging population and their families in Pennsylvania. Ms. Herold has the management experience to navigate any health system. As Clinical Manager of the acute care unit at Butler Memorial Hospital, she supervised the pilot project to privatize the community health clinic in Butler County. Ms. Herold next joined the Visiting Nurses of Western Pennsylvania where she was Manager of Complete Care Services, managed the private duty division, handled personnel issues for 80-110 employees, developed contracts and provided services to private pay individuals, insurance companies, private industry and waiver programs. In October 2011, she was named Director of the Butler County Area Agency on Aging. Ms. Herold is responsible for the financial management to meet both state and county standards and to ensure that quality programs are available to meet the needs of individuals 60 and older in Butler County. She holds a Bachelor of Science in Nursing from Gannon University and an MBA in Healthcare from Chatham University.

## **Senator Shirley M. Kitchen**

Senator Shirley M. Kitchen was elected to the Senate of Pennsylvania on November 5, 1996. She subsequently won four-year terms in November 2000, 2004, 2008 and 2012. Sen. Kitchen has proven to be an indefatigable advocate for her constituents in the 3<sup>rd</sup> District in Philadelphia County. She serves as the Democratic Chair for the Public Health and Welfare Senate Committee. She is also a member of the Senate committees on Agriculture and Rural Affairs, Policy, Transportation, Urban Affairs & Housing, Veterans Affairs and Emergency Preparedness. Sen. Kitchen was also appointed to the Advisory Committee on Geriatric and Seriously Ill Inmates and the Pennsylvania Leadership Academy. Sen. Kitchen’s crusade on behalf of the poor and disadvantaged has been a long and fruitful one. She has battled for

daycare funding, housing for low-income families, community job opportunities and predatory lending as well as teenage suicide prevention. She received her Bachelor of Arts degree in Human Services from Antioch University.

### **Cynthia A. Lambert, M.Ed.**

A native of Allentown, Cynthia A. Lambert is Vice President for Government & Community Relations at Good Shepherd Rehabilitation Network (GSRN), a Lutheran faith-based comprehensive medical rehabilitation network in the Lehigh Valley. Ms. Lambert is responsible for developing productive relationships with government and the community-at-large. She educates officials on public policy issues, legislation and regulations that affect persons with disabilities. Ms. Lambert was responsible for GSRN's multi-million dollar development program; and has also secured more than \$9 million in both capital and program funding to advance the work of the rehabilitation network. Ms. Lambert served as a Commissioner of Lehigh County from 2002-2004. A graduate of Muhlenberg College and Lehigh University, Ms. Lambert worked 12 years in county government and served as the Director of the Department of Human Services for Lehigh County. She conducted oversight of two county nursing homes, was Executive Administrator for the Area Agency on Aging, Mental Health and Mental Retardation Services, Drug and Alcohol Abuse Prevention, Children and Youth Services, and Adult and Residential Services.

### **David C. Leader**

David Leader is currently the President and Chief Operating Officer at Providence Place Senior Living. Previously he was the Chief Operating Officer at Country Meadows Retirement Communities where he was responsible for the operations of 11 campuses of senior care communities providing services to more than 3,000 customers in Personal Care/Assisted Living, Skilled Nursing, Memory Care, Independent Living and Home care services. Under David's leadership, Country Meadow's Connections™ Memory Support program has grown to serve more than 800 Pennsylvania seniors with Alzheimer's disease (or other related forms of dementia) to live life as fully as possible. This program, covering all levels of care from home care to skilled nursing, includes specialized spiritual support, fitness programs, dining accommodations and therapeutic activities – all under the guiding umbrella of a Validation© approach to communication. Prior to joining Country Meadows in 2002, David worked in International Marketing, Manufacturing Management and Oil Exploration with Fortune 500 firms. He attended Princeton University, where he received a BSE in Engineering and BA in Geology, and later earned his MBA from the Wharton School of Business.

### **Robert F. Marino**

Robert Marino has been a volunteer with the Alzheimer's Association since 2000, and a member of its Delaware Valley Chapter Board of Directors since 2004. He chairs the chapter's Southeastern Pennsylvania Advocacy Committee and also serves as Co-Chair of the Pa. Public Policy Coalition, the advocacy arm of Pa.'s two Alzheimer's Association chapters. Most recently he became a National Board Member of the Alzheimer's Impact Movement (AIM). With more than 30 years of experience in management training, and telecommunications as principal of

RFM Development, the Lafayette Hill resident was honored with the Association's Maureen Reagan Outstanding Advocate Award in 2006. Robert has a strong personal connection to Alzheimer's disease, losing both parents to the disease in 2000 and 2010. His dedication to raising awareness about Alzheimer's disease among lawmakers, in order to secure legislative action, resulted in: passage of Pa.'s MEPAS (Missing Endangered Person Advisory System); one of the highest large-state percentages of Congressional co-sponsorships for the National Alzheimer's Project Act, signed into law by President Obama, Dec. 2010; and, the first change to the PA Family Caregiver Support Act since inception, signed into law by Governor Corbett, Dec. 2011.

### **Cheryl A. Martin**

Cheryl A. Martin is Chief of Staff in the Pennsylvania Department of Public Welfare's Office of Long-Term Living. In this position, she leads performance management and data analytics, personnel administration, process re-engineering, program development and implementing strategic initiatives. She oversees the Pennsylvania's All-Inclusive Care for the Elderly (PACE) Program, called Living Independently for Elders (LIFE) in Pennsylvania. From 2010 to January 2013, Ms. Martin was the OA/OIT Enterprise Project Manager in the Secretary's office, DPW. Directly preceding this position she was Information Technology Portfolio Manager for Children and Families for which she managed an annual IT budget in excess of \$30 million annually. Rounding out her immersion in the challenge of re-balancing Pa.'s long-term-care continuum, Ms. Martin served as Director of the Home and Community-Based Services Project for the Department of Public Welfare and served as Long Term Care Advisor to the Secretary of the Pennsylvania Department of Aging. Cheryl Martin earned a BS in Management from Indiana University of Pennsylvania; a post baccalaureate degree in Accounting from Elizabethtown College; a Master of Public Administration (MPA) from the University of Pittsburgh; and retains a Project Management Professional (PMP) certification.

### **Senator Bob Mensch**

Senator Bob Mensch represents the 24<sup>th</sup> District (Bucks, Lehigh, Montgomery and Northampton counties), with more than 35 years of leadership, business, management and public service experience. He is Chairman of the Senate Aging and Youth Committee, and Vice-Chairman the Senate Public Health and Welfare Committee. A member of four other Senate Committees: Appropriations, Communications and Technology, Intergovernmental Operations, and Veterans Affairs and Emergency Preparedness. Prior to his election to the state Senate, Senator Mensch served in the Pennsylvania House of Representatives for the 147<sup>th</sup> Legislative District. He also has oversight as a co-chair of the Senate Economy, Business and Jobs Caucus, as well as chair of the Legislative Budget and Finance Committee. In addition, Senator Mensch has long been dedicated to preserving Pennsylvania's farmland and open space, as well as improving the transportation infrastructure. With a firm understanding of issues facing the Commonwealth and his natural strength as an advocate, Sen. Mensch is poised to take on the major challenges that will characterize the work of the Pennsylvania Alzheimer's Disease Planning Committee.

### **Robin Mozley**

Robin Mozley of the Lutheran Services Society has been the Manager of the Jeannette Senior Center in Westmoreland County since 2006. Her scope of work ranges from supervision of the cook, van driver, volunteers, to all aspects of kitchen duty, including food safety and sanitation procedures set forth by the Departments of Public Welfare and Agriculture, training personnel, coordination of center activities such as exercise and nutrition classes, fundraising, scheduling speakers, health screenings and fairs, computer classes, and tax preparation. Other trainings for which she has oversight include CPR and First Aid Certifications, Serve Safe training, Food Safety training by Nutrition, Inc. and training for the development and implementation of new programs for seniors by the Westmoreland County Area Agency on Aging. Ms. Mozley was well equipped to take on the herculean tasks demanded by her position at Jeannette Senior Center after seven years as the Seton Hill Child Services Food Manager. Robin Mozley earned an Associate Degree in General Business from the Penn Commercial School of Business.

### **Heidi Owen**

Director of Hospice/Oncology Services, Neighborhood Health Agencies, Inc. – West Chester, Ms. Owen has more than twenty-five years of combined nursing experience in hospice, home care, and multiple critical care areas. Currently she manages 200 hospice team members, establishes and maintains the hospice budget, markets the agency to physicians, vendors and hospitals. In addition she conducts community outreach and understanding of what hospice brings to the life journey. She is also an expert in implementing the inpatient hospice unit as well as outpatient palliative care programs. Heidi Owens is the ‘nurse’s nurse’ in flexibility, competence, team player and management credentials. Her experience throughout intensive care settings has made her the essential medical professional equipped to lead patients and colleagues to new horizons in medical and hospice care. The Pennsylvania resident earned a Bachelor of Science in Nursing from Radford University, Virginia, in 1986.

### **Maura L. Pelinsky**

From 1994 to the present, Maura Pelinsky has served as the Adult Day Services Director of Saint Mary’s East in Erie County. During her tenure she has increased clientele enrollment, creation and usage of services, maintained financial stability and received multiple deficiency-free inspections. While Assistant Director of Activities at St. Mary’s, Ms. Pelinsky, a professional violinist with the Erie Philharmonic from 1985 to the present, placed special emphasis on music, having practiced as a music therapist at the Rouse-Warren County Home in Youngsville, Pennsylvania. Other highlights of her career include committees and affiliations with the Erie Philharmonic Board of Directors, Pa. Adult Day Services Assoc., American Music Therapy Assoc., Caregivers Coalition of Erie County, National Council on Aging, American Society on Aging, and Alzheimer’s Support Group Facilitator. Ms. Pelinsky is also an Adult Instructor contracted by the Personal Care Resource Center, Inc. to develop and teach subjects for Personal Care Administrators’ certification requirements. She holds a Bachelor of Science in Music Therapy, Cum Laude, from the State University College of New York at Fredonia and a Graduate Certificate in Management from The Pennsylvania State University.

### **Charles F. Reynolds III, MD**

Charles F. Reynolds III, MD, is the University of Pittsburgh Medical Center (UPMC) Endowed Professor in Geriatric Psychiatry at UPSM and Professor of Behavioral and Community Health Sciences at the Graduate School of Public Health. He directs the Aging Institute of the UPMC and the NIMH sponsored Center of Excellence in the Prevention and Treatment of Late Life Mood Disorders. Dr. Reynolds is internationally renowned as the recipient of a National Institute of Mental Health (NIMH) Research Scientist Award and a MERIT award for Maintenance Therapies in Late-Life Depression. He has been named several times as one of The Best Doctors in America and is the 2012 recipient of the APA Jack Weinberg Award for lifetime contributions to geriatric psychiatry. Dr. Reynolds graduated magna cum laude from the University of Virginia before earning his medical degree from Yale University School of Medicine in 1973. His writings include 625 publications in peer-reviewed journals such as JAMA, the New England Journal of Medicine, and The Lancet. Associate Editor of American Journal of Geriatric Psychiatry, Dr. Reynolds has also served on the board, American Journal of Psychiatry and Archives of General Psychiatry.

### **Representative Steve Samuelson**

Rep. Steve Samuelson is the Democratic Chair of the House Aging and Older Adult Services Committee, a committee he has served on since first becoming the state representative for the 135<sup>th</sup> Legislative District in 1999. Serving the state's senior citizens has always been a priority, as exemplified by the fact that his constituent service office assisted more than 800 senior households with the property tax and rent rebate program last year, and may surpass that figure this year. Before his election, Rep. Samuelson was a legislative aide and clerk to the board for the Lehigh County Commissioners from 1989 to 1998, an experience that gives him a great understanding of the challenges facing local governments. A Bethlehem resident, Rep. Samuelson earned a bachelor's degree in government from Lehigh University and is a graduate of Leadership Lehigh Valley. He has always been active in his community having served as a PTA Board member at Spring Garden Elementary School, president of the Bethlehem Area Jaycees and a board member of Habitat for Humanity of the Lehigh Valley.

### **Jill Fortinsky Schwartz**

Ms. Schwartz is the owner of Fortune Fabrics, Inc, a weaving mill in North East Pennsylvania. She is also the owner of Gosh Yarn It!, a beautiful yarn boutique. Currently, she is Vice-Chair of the Luzerne Bank, on the board of Penn State Wilkes-Barre, and a co-founder of Circle 200, a leadership group for senior-level executive women. She has been on several community boards and has served on their financial and investment committees. She has chaired the Alzheimer's An Affair to Remember sponsorship drive for the past three years. Ms. Schwartz is a past Athena winner, sponsored by the Wilkes-Barre Chamber of Commerce, and was named one of the top women in business. She is a graduate of Meyers High School and earned her Bachelor of Science and Masters Degrees from Boston University.

### **Stuart H. Shapiro, MD**

Dr. Shapiro has a Medical Degree with honors from the State University of New York at Buffalo and a Masters Degree in Public Health from Harvard University and is Board Certified in Radiology, Nuclear Medicine, and Public Health. He has authored numerous articles on management and healthcare. Dr. Shapiro has enjoyed a successful and diversified career as a businessman and entrepreneur, a top government official and a physician. In both the public and private sectors, he has had extensive experience in public policy development, fund raising, and in media/crisis management. Since mid-2006, Dr. Shapiro has been the President and CEO of the Pennsylvania Health Care Association (PCHA), a statewide advocacy organization representing the elderly and disabled as well as their providers of care. He has been on the faculty of Harvard Medical School, Harvard School of Public Health, the Wharton School at the University of Pennsylvania, and Georgetown University School of Medicine. Dr. Shapiro is currently a member of the Board of Visitors of the Temple University College of Health Professions and Social Work.

### **John Q. Trojanowski, MD, PhD**

Dr. Trojanowski obtained his MD/PhD in 1976 from Tufts University Boston. He has held numerous major leadership positions at the University of Pennsylvania: Previously: Principal Investigator of a NIA Program Project Grant on Alzheimer's and Parkinson's disease (1990-2010), Director of Medical Pathology (1988-2002). Currently he is Director of a National Institute of Aging (NIA) Alzheimer's Disease Core Center (1991-present). Director (2002-present) of the Institute on Aging, founding Co-Director (1992-present) of the Center for Neurodegenerative Disease Research; Director, National Institute of Neurological Disorders and Stroke (NINDS) Morris K. Udall Parkinson's Disease) Research Center of Excellence (2007-present), the first William Maul Measey-Truman G. Schnabel, Jr., M.D., Professor of Geriatric Medicine and Gerontology (2003-present), Co-director of the Marian S. Ware Alzheimer Drug Discovery Program (2004-present). Dr. Trojanowski has received many awards for his research, from a MERIT Award (1986-1994) from the National Institutes of Health (NIH), to the 2012 John Scott Award (established in 1822; given for inventions contributing in some outstanding way to the "comfort, welfare and happiness" of mankind by the City of Philadelphia). Because of the broad impact of his research, Dr. Trojanowski is among the top 10 most highly cited Alzheimer's Disease researchers, and he has been recognized as ISI Highly Cited Researcher, which has placed him among the top 10 most highly cited neuroscientists from 1997 to 2007.

### **Senator Patricia H. Vance**

Sen. Patricia H. Vance is the only professional nurse in the Pennsylvania Legislature. She has been a member of the Senate since 2005, having served 14 years in the Pennsylvania House of Representatives. She is chair of the Senate's Public Health and Welfare Committee and a member of the Appropriations, Banking and Insurance, Communications and Technology, Consumer Protection and Professional Licensure, Finance and Policy committees. She also serves on the Capitol Preservation Committee. Sen. Vance has authored 16 laws. Among them: defining procedures for filing complaints of abuse, neglect and exploitation of adults with cognitive or physical disabilities; requiring nurses to obtain 30 hours of continuing education every two years; and blending the state's prescription drug program for low-income seniors with Medicare Part D. While a member of the House, she authored more than a dozen laws. Among

them, originating an HMO bill of rights; prohibiting discrimination against domestic violence victims by insurance companies; expanding the Commonwealth's prescription drug program for 100,000 low-income seniors. Sen. Vance has received numerous awards for her legislative and community stewardship. Each reflects her concern and commitment to the individual, the family, and older adults.

### **Senator LeAnna M. Washington**

Senator LeAnna M. Washington is the Minority (Democratic) Chair of the Senate's Aging and Youth Committee. She has served on the Appropriations, Urban Affairs and Housing, Veterans Affairs and Emergency Preparedness committees. For two decades Sen. Washington has been a driving force in the community and continues to work diligently for her constituents. She began her political career in 1993 when she won a special election seat serving the 200th District; she served in the Pennsylvania House of Representatives for 12 years before winning the seat in the Pennsylvania Senate serving the 4th Senatorial District, parts of Montgomery and Philadelphia counties. Although Senator Washington experienced some daunting early life challenges, her tenacity, perseverance, and faith in God have led her from victim to survivor to success. One of the Senator's priorities for the 2013-2014 legislative session is elder caregiver background checks. Sen. Washington has been honored on numerous occasions for community and civic contributions. She holds a Master's degree in Human Services from Lincoln University.

# SUMMARY OF RESOURCES FOR PERSONS WITH ADRD AND CAREGIVERS

## Pennsylvania Alzheimer's Disease Planning Committee

The purpose of this inventory is to summarize the existing resources for addressing the needs of persons with Alzheimer's disease and related disorders (ADRD) and their caregivers. *Please note that this inventory is evolving and not all inclusive.*

## Pennsylvania Departments Related to ADRD:

### **Pennsylvania Department of Aging**

The Pennsylvania Department of Aging was created in 1979 to advocate for Pennsylvania's rapidly growing older population. Through a statewide network of 52 Area Agencies on Aging, the department provides many benefits and services to Pennsylvania's 2.7 million people over the age of 60. The population continues to grow each year, with the 85 and older population the fastest growing segment. As we move forward, the department will continue its mission: enhancing the quality of life of the communities, families and older people of Pennsylvania.

The Department of Aging can be contacted at:

555 Walnut Street, 5<sup>th</sup> Floor  
Harrisburg, PA 17101-1919  
(717) 783-1550

[http://www.aging.state.pa.us/portal/server.pt/community/department\\_of\\_aging\\_home/18206](http://www.aging.state.pa.us/portal/server.pt/community/department_of_aging_home/18206)

### **Area Agencies on Aging (AAA)**

The Area Agencies on Aging are the local representatives of the Pennsylvania Department of Aging and serve as the front doors for aging services at the local level. Area Agencies on Aging were established by the Older Americans Act and operate in 52 planning services areas encompassing all 67 counties of the Commonwealth. They serve as the local resources providing information and assistance on issues and concerns affecting older individuals and their caregivers.

The AAAs complete assessments to determine which programs/services best meet the needs of individuals seeking assistance in the community. They are the entry point for individuals seeking medical assistance payment for nursing facilities and in home care. The AAA also provide services to older eligible consumers through the OPTIONS program which includes assisting in maintaining independence with the highest level of function in the community. For more information on the OPTIONS program please contact your local AAA. To find your local AAA, please visit the website below.

[http://www.aging.state.pa.us/portal/server.pt/community/your\\_local\\_resources/17952](http://www.aging.state.pa.us/portal/server.pt/community/your_local_resources/17952)

### **PACE, PACENET, Medicare Part D & Academic Detailing**

PACE, PACENET are Pennsylvania's prescription assistance programs for older adults, offering low-cost prescription medication to qualified residents, age 65 and older. For information, call 1-800-225-7223 or visit the PACE website to view and download an application.

[http://www.portal.state.pa.us/portal/server.pt/community/pace\\_and\\_affordable\\_medications/179](http://www.portal.state.pa.us/portal/server.pt/community/pace_and_affordable_medications/179)

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## **PACE**

- For a single person, total income must be \$14,500 or less
- For a married couple, combined total income must be \$17,700 or less
- Prescription drugs, including insulin, insulin syringes & needles
- Generic medications: \$6 Copay (30-day supply)
- Brand name medications: \$9 Copay (30-day supply)
- Can get a 90-day supply with PACE & Part D

## **PACENET**

- PACENET income limits are slightly higher than those for PACE
- For a single person, total income can be between \$14,500 and \$23,500
- For a married couple, combined total income can be between \$17,700 and \$31,500
- Prescription drugs covered including insulin, insulin syringes & needles
- Generic medications: \$8 copay (30-day supply)
- Brand name medications: \$15 copay (30-day supply)
- Can get 90-day supply with Part D
- Pay PACENET deductible or Part D monthly premium

## **Medicare Part D**

- PACE/PACENET coordinates benefits with Part D
- No coverage gap
- Lower copayments
- Program pays Part D premium for most PACE cardholders
- Part D deductible coverage for members with Part D
- PACE/PACENET is creditable coverage

## **Medicare Part D Extra Help/Low Income Subsidy**

- Enrollees with low income and few assets
- Provides for no or reduced Part D premium and deductible
- No coverage gap
- Low copayments
- Contact PACE for help applying.

## **Interventions—Utilization Review, Academic Detailing and Caregiver Support**

The overuse and misuse of prescription drugs to treat ADRD is all too common. The PACE program supports patient safety in three ways. Physicians and pharmacists, have, over twenty years, constructed a unique comprehensive and aggressive drug utilization

review which screens cardholder prescriptions for effectiveness in dose, duration and concurrent usage. This review crosses over many disease states and includes psychotropic drug use. The goal is optimal therapy at the pharmacy counter prior to dispensing, with special considerations for the drug therapy of older patients.

The Academic Detailing program reaches out to the prescribers in their offices with face to face interactive discussion and follows up visits. At the visit, the drug educator gives specific, practice changing recommendations to continue, discontinue or modify prescription drug use. CME credit is available for each topic. Pennsylvania is the only state in the country to utilize this program. Topics are also offered online for CME credit. One of the 2014 education modules addresses ADRD.

In 2014, the PACE Program will offer a dementia care management program for its cardholders. Care management improves the functioning and wellbeing of older adults with ADRD and of their informal caregivers. This program aims to enhance caregiver coping ability, reduce distress caused by behavioral and psychological symptoms, decrease nursing home placement rates and increase time to nursing home placement.

For more information contact the PACE Program at 1-800-225-7223.

### **Adult Day Care**

Adult day services centers offer an interactive, safe, supervised environment for older adults and adults with ADRD, Parkinson's disease or other organic brain syndromes. Adult day services centers offer a community-based alternative to institutionalization and provide a reliable source of support and respite for caregivers. All adult day centers in Pennsylvania provide personal care, nursing services, social services, therapeutic activities, nutrition and therapeutic diets and emergency care. Some centers offer additional services such as physical therapy, occupational therapy, speech therapy, medical services, podiatry, etc. to meet the range of client needs. For more information on Adult Day Care visit the website below.

<http://www.portal.state.pa.us/portal/server.pt?open=514&objID=616554&mode=2>

### **Domiciliary Care Services for Adults**

Domiciliary Care is a supervised living arrangement in a home-like environment for adults who are unable to live alone because of demonstrated difficulties: 1) in accomplishing activities of daily living, 2) in social or personal adjustment, or 3) resulting from disabilities. The Area Agency on Aging is responsible for certifying homes and for assessment and placement of residents in domiciliary care homes. Residents are eligible for a domiciliary care supplement payment if they are eligible for Supplemental Security Income (SSI) or have an income less than the combined federal/state payment for domiciliary care and are not related to the provider. People who are not eligible for the supplement may reside in domiciliary care homes as private pay residents. Please contact your local Area Agency on Aging for more information on Domiciliary Care Services for Adults. To find your local Area Agency on Aging visit:

[http://www.aging.state.pa.us/portal/server.pt/community/your\\_local\\_resources/17952](http://www.aging.state.pa.us/portal/server.pt/community/your_local_resources/17952)

## **Elder abuse**

Elder abuse and crimes targeting older people are a real issue that comes in many forms, including neglect, physical, financial and sexual abuse. Learn how to stay safe and report suspected abusers. Statewide elder abuse hotline: 1-800-490-8505

[http://www.portal.state.pa.us/portal/server.pt/community/abuse\\_or\\_crime/17992](http://www.portal.state.pa.us/portal/server.pt/community/abuse_or_crime/17992)

## **Pennsylvania Caregiver Support Program**

The Pennsylvania Caregiver Support Program provides benefits to primary caregivers to relieve caregiver burden. Prospective consumers should contact their county Area Agency on Aging (AAA). The AAA will assess the needs of the caregiver, degree of caregiver burden, the needs of the care receiver and the caregiving environment. Other services may include reimbursement for supplies/services paid for by the caregiver, counseling, information and referral to other area services, caregiver education/training and respite.

<http://www.portal.state.pa.us/portal/server.pt?open=514&objID=616680&mode=2>

## **Pennsylvania Department of Health**

### **Nursing Care Facility Locator**

The Pennsylvania Department of Health Nursing Care Facility Locator allows you to find nursing care facilities by county, city or zip code.

<http://app2.health.state.pa.us/commonpoc/nhLocator.asp>

### **Nursing Home Complaint Hotline**

The Department of Health is available to assist you if you're concerned about quality of care in a nursing home. First, we recommend you talk to your Nursing Home Administrator and/or Director of Nursing. He or she is licensed and responsible for the operation of the facility. The facility is required to have a system in place to address your concerns and develop a plan to lead a reasonable and acceptable solution. Second, you should call your local Area Agency on Aging. A trained professional will help resolve the issue or contact the proper authority, if necessary. If you are still dissatisfied, the Department of Health will assist you in assuring quality of care and safety for nursing home residents. They have a toll-free hotline staffed by trained individuals Monday through Friday, from 8am-4:30pm. Call 1-800-254-5164

For complaints regarding a Personal Care Home or an Assisted Living Facility call: 1-877-401-8835

For more information visit:

[http://www.portal.health.state.pa.us/portal/server.pt/community/nursing\\_home\\_care/14152](http://www.portal.health.state.pa.us/portal/server.pt/community/nursing_home_care/14152)

## **Pennsylvania Department of Insurance – Long- Term Care Insurance**

Long-Term Care (LTC) insurance is one option many people choose to provide financial protection when they can no longer perform the most basic functions of daily activity. LTC

insurance coverage in Pennsylvania provides services in your home, a medical facility or a combination of the two.

[http://www.portal.state.pa.us/portal/server.pt/community/health\\_insurance/9189/long\\_term\\_care/591838](http://www.portal.state.pa.us/portal/server.pt/community/health_insurance/9189/long_term_care/591838)

### **Pennsylvania Department of Military and Veterans Affairs (DMVA)**

Pennsylvania's Department of Military and Veterans Affairs (DMVA) has a dual mission: to provide quality service to the Commonwealth's veterans and their families, and to oversee and support the members of the Pennsylvania National Guard.

[http://www.dmva.state.pa.us/portal/server.pt/community/dmva\\_home/5902](http://www.dmva.state.pa.us/portal/server.pt/community/dmva_home/5902)

### **Pennsylvania Department of Public Welfare**

<http://www.dpw.state.pa.us/>

#### **Aging Waiver**

The Aging Waiver Program provides in-home services to consumer, age 60 and over, who meet functional and financial eligibility requirements and would like to receive services at home.

- Assessment of need for provision of services and service coordination to persons 60 years of age or older who are determined to be clinically eligible through a formal needs.
- Determined financially eligible for Medicaid nursing facility payment but chooses community services.

[www.ltlinPA.com](http://www.ltlinPA.com)

#### **Nursing Home Transition Program**

If you or someone you love resides in a nursing facility and would like to return home, support exists that can make that happen. There are Home and Community Based Services available to you or your loved one to help with daily living needs. Your local Area Agency on Aging, Center for Independent Living or disability service organization can provide information about additional resources. These resources can be used to pay for the necessary expenses to establish your basic living arrangements and help you move into the community. The agency can also help to locate housing, assist with home modifications and arrange for in-home care. Contact your local Area Agency on Aging for more information regarding the Nursing Home Transition Program.

## Pennsylvania Organizations Related to ADRD

### **Pennsylvania Alzheimer’s Association Chapters**

The Alzheimer’s Association provides comprehensive care, support, and disease information to families and individuals throughout Pennsylvania via its two state chapters in 8 regional offices. Their 24/7 helpline will direct you to the chapter serving your community: 1-800-272-3900

#### **Greater Pennsylvania Chapter:**

2595 Interstate Drive Suite 100

Harrisburg, PA. 17110

<http://www.alz.org/pa>

#### **Delaware Valley Chapter:**

399 Market St. Suite 102

Philadelphia, PA. 19106

<http://www.alz.org/desjsepa/>

### **Drexel Neurology – Memory Disorders, Dementia, and Alzheimer's Services**

The Drexel memory disorders program in Philadelphia offers expert treatment for patients with Alzheimer's disease and other forms of dementia or cognitive loss.

<http://www.drexelmedicine.org/patient-services/neurology/services/memory-disorders/>

### **Jefferson Elder Care**

Jefferson Elder Care offers home-based services and professional training, all focused on the same goal: improving the daily lives of older adults and their families. Developed by experts at Thomas Jefferson University, our research-based programs improve caregiver skills and reduce the need for assistance, help those with memory loss and other cognitive impairments perform their daily activities, and enhance the safety and daily function of older adults living at home.

[http://www.jefferson.edu/health\\_professions/elder\\_care.html](http://www.jefferson.edu/health_professions/elder_care.html)

### **LeadingAge, PA**

LeadingAge PA is a trade association representing Pennsylvania not-for-profit organizations that provide housing, healthcare and community services primarily to the elderly. Founded in 1963, the Pennsylvania Association of Non-Profit Homes for the Aging – now LeadingAge PA - was established to provide education and a voice of advocacy for not-for-profit long term care providers.

<http://www.leadingagepa.org/Home.aspx>

### **Northeast Pennsylvania Memory & Alzheimer’s Center**

The Northeastern Pennsylvania Memory and Alzheimer’s Center is the premier facility in Northeast Pennsylvania created for and dedicated to identifying and treating memory disorders and dementia. We provide comprehensive highly personalized medical care and compassionate support for our patients and families suffering from the effects of all types of dementia.

[http://memalzctr.org/Home\\_Page.html](http://memalzctr.org/Home_Page.html)

## **Pennsylvania Adult Day Services Association**

Established in 1982, PADSA is an organization of providers and concerned individuals interested in the promotion of quality adult day services in Pennsylvania. More than 100 centers and individuals are represented by PADSA in meetings with key policy makers and legislators. PADSA center members are also members of the National Adult Day Services Association (NADSA).

<http://www.padsa.org/index.htm>

## **Pennsylvania Association of Senior Centers**

The Pennsylvania Association of Senior Centers (PASC) mission is revitalizing and empowering senior centers across Pennsylvania to be able to provide comprehensive customer service to meet the needs of seniors in their communities.

<http://www.pascpulse.org/>

## **Pennsylvania Healthcare Association**

The Pennsylvania Health Care Association (PHCA) and its companion organization, the Center for Assisted Living Management (CALM), advocate for compassionate, quality long-term care for Pennsylvania's elderly and disabled residents. PHCA and CALM serve as leaders within the profession, providing advocacy, information, and education designed to enhance quality for those residing or recuperating in members' facilities. PHCA/CALM also provides educational opportunities through the year in which continuing education credits can be earned. These opportunities are offered both online and through seminars and convention. Membership in PHCA and CALM consists of non-profit, for-profit, and county owned nursing homes, assisted living facilities, and personal care homes.

PHCA also maintains a "world-class" facility finder for use of those seeking care or those wanting to help a loved one find care in the appropriate setting.

<http://www.phca.org/>

## **Pennsylvania Homecare Association**

The Pennsylvania Homecare Association is a state trade association representing more than 500 organizations that provide care and support to individuals in their own homes.

<http://www.pahomecare.org/>

## **Pennsylvania Hospice Network**

The Pennsylvania Hospice Network was established in 1979 and incorporated in 1980 to provide an organizational structure for hospice programs in the Commonwealth of Pennsylvania. The first meeting, held in 1980, was sponsored by the American Cancer Society. Today, PHN has grown to more than 200 organizational and individual members state-wide.

<http://www.pahospice.org/index.htm>

## **Penn Memory Center**

The Penn Memory Center is a single, unified Penn Medicine source for those ages 65 and older seeking evaluation, diagnosis, treatment, information, and research opportunities related to symptoms of progressive memory loss, and accompanying changes in thinking, communication and personality.

<http://pennadc.org/>

## **Penn State Center for Healthy Aging**

The Center for Healthy Aging conducts and supports research, outreach and educational activities focused on promoting health and well-being from early adulthood into later-life.

<http://healthyaging.psu.edu/>

## **Premise Alert System**

The Premise Alert System was created in 2004 to provide a standard method to alert first responders of the presence and needs of individuals with special needs or disabilities (including ADRD) within a community.

<http://www.operationtakemehome.org/otmh/Other%20Safety%20Forms/PA%20Premise%20Alert.pdf>

## **University of Pittsburgh Aging Institute**

The Aging Institute of UPMC Senior Services and the University of Pittsburgh provides access to a multidisciplinary network of comprehensive clinical care, one of the nation's largest and most diverse portfolios of aging-related research, and one of the most extensive geriatric and gerontologic education programs in the country. The Aging Institute also acts as a referral resource, connecting users with information on aging-related topics, educational programs, research studies, and services. This website offers a broad array of information that has been categorized by audience into five main sites: Older Adults, Family and Caregivers, Professionals in Aging, Researchers, Educators and Students.

<http://www.aging.pitt.edu/>

## **University of Pittsburgh Alzheimer's Disease Research Center**

The University Of Pittsburgh Alzheimer Disease Research Center (ADRC) is one of the nation's leading research centers specializing in the diagnosis of Alzheimer's disease and related disorders. Through outpatient evaluations, participants and their families receive state-of-the-art diagnostic assessments and contribute to the scientific study of Alzheimer's disease.

<http://www.adrc.pitt.edu/>

## National Organizations Related to ADRD

### **Alzheimer's Association**

The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support and research. The mission of the Alzheimer's Association 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.

[www.alz.org](http://www.alz.org)

### **Alzheimer's Association 24/7 Helpline**

Helpline for information about ADRD, treatment and care options. Call at (1.800.272.3900)

### **Alzheimer's Association- Caregiver Center**

A comprehensive web portal providing caregiving tools, tips & self-study information for all stages of the disease process.

<http://www.alz.org/care/overview.asp>

### **Alzheimer's Association- I have Alzheimer's Disease**

Developed with input from with people living with the disease, the Alzheimer's Association's launched *I have Alzheimer's*, a new 23-page web section on alz.org. *I have Alzheimer's* is designed to help empower those living in the early stage of the disease to move past the feeling of isolation that often comes with a diagnosis and on to planning, preparing, receiving support and living their best life after diagnosis.

<http://www.alz.org/i-have-alz/i-have-alzheimers-dementia.asp>

### **Alzheimer's Disease Education and Referral Center (ADEAR)- National Institute on Aging**

The U.S. Congress created the Alzheimer's Disease Education and Referral (ADEAR) Center in 1990 to "compile, archive, and disseminate information concerning Alzheimer's disease" for health professionals, people with AD and their families, and the public. The ADEAR Center is a service of the National Institute on Aging (NIA), one of the Federal Government's National Institutes of Health and part of the U.S. Department of Health and Human Services. The NIA conducts and supports research about health issues for older people, and is the primary Federal agency for Alzheimer's disease research. As a public, U.S. Government-funded resource, the ADEAR Center is a current, comprehensive, unbiased source of information about Alzheimer's disease. Call toll free: 1-800-438-4380

<http://www.nia.nih.gov/alzheimers/>

## **Alzheimer's Foundation of America**

AFA unites more than 1,600 member organizations from coast-to-coast that are dedicated to meeting the educational, social, emotional and practical needs of individuals with Alzheimer's disease and related illnesses, and their caregivers and families. Under AFA's umbrella, these organizations collaborate on education, resources, best practices and advocacy—all resulting in better care for people affected by the disease. Call toll free: 866.AFA.8484

<http://www.alzfdn.org/>

## **Alzheimer's International**

ADI is the international federation of Alzheimer associations around the world, in official relations with the World Health Organization. Each member is the Alzheimer association in their country who support people with dementia and their families. ADI's vision is an improved quality of life for people with dementia and their families throughout the world.

<http://www.alz.co.uk/>

## **Alzheimers.gov**

A clearinghouse offered by Health and Human Services that is a way for caregivers and those living with the disease to easily find assistance. The website focuses specifically on four key areas. 1) Understanding and viewing treatment options. 2) Planning ahead for long term care and understanding insurance coverage. 3) Access to free telephone helplines, in-home help, day care and respite services. 4) Access to research and programs aimed at reducing the burden to Alzheimer's disease.

<http://www.alzheimers.gov/>

## **Alzheimer's Speaks**

Alzheimer's Speaks believes collaboration is the key to living a successful and purpose filled life with dementia. By working together, we can push both conventional and alternative efforts forward in search of answers. By joining forces and sharing knowledge, we can win the battle against dementia. Call at: 651-748-4714

<http://www.alzheimersspeaks.com/>

## **American Psychological Association –Office on Aging**

The Office on Aging is a coordination point for APA activities pertaining to aging and geropsychology (the field within psychology devoted to older adult issues). The Office on Aging also supports the work of the APA Committee on Aging.

<http://www.apa.org/pi/aging/>

## **Center for Advocacy for the Rights and Interest of the Elderly (CARIE)**

The Center for Advocacy for the Rights and Interests of the Elderly (CARIE) is a non-profit organization, based in Philadelphia, dedicated to improving the quality of life for vulnerable older people. Setting CARIE apart from others in the aging field is its sole focus on advocacy through a comprehensive array of activities, community education programs, professional

training and consultation, and referral using a client-centered approach. Its services are provided locally, throughout the Commonwealth of Pennsylvania and in some cases nationally. Call: 215-545-5728

<http://www.carie.org/>

### **Centers Medicare & Medicaid Services (CMS) Partnership to Improve Dementia Care in Nursing Homes**

On March 29, 2012, CMS launched a national partnership with the mission to improve quality of care provided to individuals with dementia living in nursing homes. This partnership focuses on the delivery of health care that is person-centered, comprehensive and interdisciplinary, in addition to protecting residents from being prescribed antipsychotic medications unless there is a valid, clinical indication and a systematic process to evaluate each individual. The partnership promotes rethinking approaches that are utilized in dementia care, reconnecting with people using person-centered care approaches and restoring good health and quality of life in nursing homes.

[http://www.nhqualitycampaign.org/star\\_index.aspx?controls=dementiaCare](http://www.nhqualitycampaign.org/star_index.aspx?controls=dementiaCare)

### **Dementia Society of America**

The Dementia Society of America (DSA) represents an important one-stop Dementia resource for individuals, professionals, companies, nonprofits, government, non-governmental organizations and others.

<http://www.dementiasociety.org/#>

### **National Association of Professional Geriatric Care Managers**

NAPGCM, a nonprofit association with over 2,000 members, is governed by a 15-member Board of Directors who are elected to two-year terms and represent a diversity in practices and geographic locations. Call: 520.881.8008

<http://www.caremanager.org/>

### **National Institute on Aging**

National Institute on Aging through the U.S. Department of Health and Human Services.

<http://www.nia.nih.gov/>

### **Promoting Positive Behavioral Health in Nursing Homes**

This toolkit promotes positive behavioral health: A nonpharmacologic toolkit for senior living communities—contains resources to help staff in senior living communities promote nonpharmacologic behavioral health strategies to address behavioral and psychological symptoms of dementia (BPSD) behaviors that frequently occur in long-term care residential settings, especially among residents with dementia.

<http://www.nursinghometoolkit.com/>

## **U.S. Against Alzheimer's**

US Against Alzheimer's is a community of engaged and enraged individuals who have been touched by Alzheimer's disease and are united by our frustration at a broken status quo. We are dedicated to mobilizing individuals to demand the urgency, passion and commitment needed by our political, business and civic leaders to achieve the goal of ending Alzheimer's by 2020. Call 202-349-3803

<http://www.usagainstalzheimerstnetwork.org/splash-join-the-movement>

## **Veterans Administration (VA)**

Overview of the variety of resources offered by the Veterans Administration (VA) such as Veteran's Pension, Survivors Program, and the Aid and Attendance Program. Call toll free: 1-877-222-8387

<http://www.benefits.va.gov/pension>

## Information about other Related Disorders

### **Alzheimer's Association- Early/Younger onset Alzheimer's disease (EOAD/YOAD)**

Alzheimer's is not just a disease of old age. Younger-onset (also known as early-onset) Alzheimer's affects people younger than age 65. Nearly 4 percent of the more than 5 million Americans with Alzheimer's have younger-onset. See the link below for more information.

[http://www.alz.org/alzheimers\\_disease\\_early\\_onset.asp](http://www.alz.org/alzheimers_disease_early_onset.asp)

### **Alzheimer's Association - Posterior cortical atrophy**

Posterior cortical atrophy (PCA) refers to gradual and progressive degeneration of the outer layer of the brain (the cortex) in the part of the brain located in the back of the head (posterior).

<http://www.alz.org/dementia/posterior-cortical-atrophy.asp>

### **American Parkinson Disease Association**

As the country's largest grassroots Parkinson's disease organization, the American Parkinson Disease Association (APDA) improves the lives people with Parkinson's disease and their families from coast to coast with patient/caregiver support; education and positive lifestyle programs; awareness, social and fundraising events; and scientific research funding at all levels. Through a national network of Chapters, Information & Referral Centers, more than 1,000 support groups, and eight Centers for Advanced Research, APDA delivers help for today and hope for tomorrow. Call toll free: 1-800-223-2732

[www.apdaparkinson.org](http://www.apdaparkinson.org)

### **Association for Frontotemporal Degeneration**

The Association for Frontotemporal Degeneration is the place to turn for accurate information, compassion and hope when lives are touched by frontotemporal degeneration. FTD, also called frontotemporal dementia or frontotemporal lobar degeneration (FTLD), is a disease process that causes a group of brain disorders characterized by changes in behavior and personality, language and/or motor skills, and a deterioration in a person's ability to function. Call toll free: 1-866-507-7222

[www.theaftd.org](http://www.theaftd.org)

### **Lewy Body Dementia Association**

Lewy Body Dementia (LBD) is an umbrella term for two related diagnoses. LBD refers to both Parkinson's disease dementia and dementia with Lewy bodies. The earliest symptoms of these two diseases differ, but reflect the same underlying biological changes in the brain. Over time, people with both diagnoses will develop very similar cognitive, physical, sleep, and behavioral symptoms. Call toll free: 1-800.539.9767

[www.lbda.org](http://www.lbda.org)

## **Michael J. Fox Foundation**

The Michael J. Fox Foundation is dedicated to finding a cure for Parkinson's disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today.

<https://www.michaeljfox.org/>

## **Parkinson Disease Foundation**

The Parkinson's Disease Foundation (PDF) is a leading national presence in Parkinson's disease research, education and public advocacy. We are working for the nearly one million people in the US who live with Parkinson's by funding promising scientific research while supporting people living with Parkinson's through educational programs and services. Since its founding in 1957, PDF has dedicated over \$100 million to fund the work of leading scientists throughout the world and over \$42 million to support national education and advocacy initiatives.

<http://www.pdf.org/>

## **Penn Parkinson's Disease and Movement Disorders Center at Pennsylvania Hospital**

The Parkinson's Disease and Movement Disorders Center (PD&MDC) is located at Pennsylvania Hospital and provides comprehensive care to patients with Parkinson's disease (PD) and other parkinsonian syndromes, dystonia, Tourette's syndrome, Huntington's disease and other movement disorders. Since its inception in 1982, it has been a regional and national leader in the care of patients with these disorders. The center is part of the Penn Medicine Neuroscience Center and is committed to exceptional patient care, professional and community education, social support services, and research.

<http://www.pennmedicine.org/neuro/services/parkinsons/>

## **Progressive supranuclear palsy- National Institute of Neurological Disorders and Stroke.**

Progressive supranuclear palsy (PSP) is a rare brain disorder that causes serious and progressive problems with control of gait and balance, along with complex eye movement and thinking problems. One of the classic signs of the disease is an inability to aim the eyes properly, which occurs because of lesions in the area of the brain that coordinates eye movements. Some individuals describe this effect as a blurring. Affected individuals often show alterations of mood and behavior, including depression and apathy as well as progressive mild dementia.

[http://www.ninds.nih.gov/disorders/psp/detail\\_psp.htm](http://www.ninds.nih.gov/disorders/psp/detail_psp.htm)

## **Clinical Trial Information**

### **Abington Neurological Associates**

<http://www.abingtonneurology.com/>

### **Alzheimer's Association-Participating in Clinical Trials**

[http://www.alz.org/research/clinical\\_trials/find\\_clinical\\_trials\\_trialmatch.asp](http://www.alz.org/research/clinical_trials/find_clinical_trials_trialmatch.asp)

### **Alzheimer's Association- Trial Match**

[www.alz.org/trialmatch](http://www.alz.org/trialmatch)

### **Clinical Trial Center, Jenkintown, PA**

<http://theclinicaltrialcenter.com/>

### **Clinicaltrials.gov**

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

### **Clinical Trials Research Services, Pittsburgh**

<http://www.ctrslc.com/>

### **Fox Trial Finder- Michael J. Fox Foundation**

<https://foxtrialfinder.michaeljfox.org/>

### **Jefferson**

<http://www.jefferson.edu/>

### **Lehigh Valley Health Network**

<http://www.lvhn.org/>

### **University of Pennsylvania Medical Center**

<http://www.pennmedicine.org/>

## Information on Specific Issues and Topics Related to ADRD

### **Alzheimer's Association- African Americans**

<http://www.alz.org/africanamerican/>

### **Alzheimer's Association- Alzheimer's disease and other dementias overview**

[http://www.alz.org/alzheimers\\_disease\\_what\\_is\\_alzheimers.asp](http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp)

### **Alzheimer's Association - Healthy Brain Aging**

[http://www.alz.org/we\\_can\\_help\\_brain\\_health\\_maintain\\_your\\_brain.asp](http://www.alz.org/we_can_help_brain_health_maintain_your_brain.asp)

### **Alzheimer's Association - Individuals with Down syndrome**

<http://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp>

### **Alzheimer's Association- Latinos**

<http://www.alz.org/espanol/overview-english.asp>

### **Alzheimer's Association-Other State Plans**

The Alzheimer's Association provides a comparison document that shows the similarities and differences between state plans.

[http://act.alz.org/site/DocServer/STATE\\_AD\\_PLANS.pdf?docID=4641](http://act.alz.org/site/DocServer/STATE_AD_PLANS.pdf?docID=4641)

### **Alzheimer's Association - Planning for the future**

Offered by the Alzheimer's Association this free source can help caregivers and those living with the disease by providing access to information, support and local resources.

[https://www.alzheimersnavigator.org/default.aspx?utm\\_source=alz.org&utm\\_medium=referral&utm\\_campaign=alz-homepage-edu-resource-center](https://www.alzheimersnavigator.org/default.aspx?utm_source=alz.org&utm_medium=referral&utm_campaign=alz-homepage-edu-resource-center)

### **Alzheimer's Association-Signs of possible dementia**

[http://www.alz.org/alzheimers\\_disease\\_10\\_signs\\_of\\_alzheimers.asp](http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp)

### **Alzheimer's Association- Online Support groups\**

The Alzheimer's Association *ALZConnected* message boards and chat rooms are your online communication forum. Our message boards have over 9,000 registered members from around the United States, and many more people who simply browse the stories and information that is offered 24 hours a day.

[http://www.alz.org/apps/we\\_can\\_help/support\\_groups.asp](http://www.alz.org/apps/we_can_help/support_groups.asp)

## **ElderCare.gov-Residential Options**

The Eldercare Locator, a public service of the Administration on Aging, U.S. Department of Health and Human Services, is a nationwide service that connects older Americans and their caregivers with information on senior services. Call at: 1-800-667-1116

<http://www.eldercare.gov/eldercare.net/public/Index.aspx>

## **LongTermCare.gov**

Service offered by the Health and Human Services through the Administration on Aging to help planning for long-term care needs. Call at: 202-619-0724

[www.longtermcare.gov](http://www.longtermcare.gov)

## **Medicaid for Nursing Home Care**

[www.medicaid.gov](http://www.medicaid.gov) or call: 1-800-633-4227

<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Nursing-Facilities-NF.html>

## **National Plan on Alzheimer's**

Health and Human Services has released a 2013 update to their National Alzheimer's Disease Plan.

<http://aspe.hhs.gov/daltcp/napa/NatPlan2013.pdf>

## **Research News**

<http://www.alz.org/research/overview.asp>

<http://www.alzforum.org/>

<http://iadrp.nia.nih.gov/cadro-web/databaseSearch>

## **Respite Care Guide- Alzheimer's Association**

An overview of respite care options provided by the Alzheimer's Association. Respite care can provide a caregiver much needed resources when they need it most.

[http://www.alz.org/national/documents/brochure\\_respitcareguide.pdf](http://www.alz.org/national/documents/brochure_respitcareguide.pdf)

## **Safety for those living with ADRD- Alzheimer's Association**

Safety is important for everyone, but taking specific precautions becomes vital as dementia progresses. By putting measures in place, you can prevent injuries and help the person with Alzheimer's disease feel comfortable.

<http://www.alz.org/care/alzheimers-dementia-safety.asp>

## Information on Legal Issues Related to ADRD

### **AARP Legal Services Network (LSN)**

AARP helps its members get the legal services they need. The AARP Legal Services Network (LSN) provides members with names of attorneys who have met LSN standards of experience and customer service. LSN attorneys offer members a free initial consultation of up to 45 minutes. All other legal services are provided 20 percent off the attorneys' usual rates. All AARP members nationwide are eligible. Call toll-free 1-866-330-0753.

[www.aarplsn.com](http://www.aarplsn.com)

### **A Guide to Legal Issues for Pennsylvania Senior Citizens**

<http://www.pabar.org/pdf/guidelegalservicessc.pdf>

### **Pennsylvania's SeniorLAW Helpline**

Older Pennsylvanians can receive free, confidential telephone legal advice and/or referrals for services to local participating lawyers by calling the SeniorLAW Helpline. Attorneys will advise callers on any civil legal matter, to the extent they are able. Limited client representation is available directly. Legal Helpline clients needing representation maybe referred to a legal aid organization in their county, their local Area Agency on Aging's legal assistance program, the PA Bar Association or another organization. Pennsylvania residents age 60 years and older are eligible.

**SeniorLaw Help line Hours of Operation:** Monday, Wednesday, Friday,  
10:00 a.m. to 2:00 p.m.

**CONTACT:** Call toll-free 1-877-PA SR LAW (1-877-727-7529) SeniorLAW Helpline  
SeniorLaw Center  
Land Title Building  
100 S. Broad St., Ste. 1810  
Philadelphia, PA 19110  
[www.seniorlawcenter.org](http://www.seniorlawcenter.org)

### **Powers of Attorney and Living Wills**

A Power of Attorney is a written document where a principal, the individual making the Power of Attorney, designates an agent to transact on the principal's behalf, if the principal becomes unable to act for himself. The agent must act in the best interest of the principal. The agent must keep the assets of the principal separate from those of the agent and keep a full, complete, and accurate record of all transactions, receipts and disbursements on behalf of the principal. In most cases, a Power of Attorney is not valid unless it is signed and dated by the principal. An advance directive is a written document that you may use, under certain circumstances, to tell others what care you would like to receive or not receive should you become unable to express your wishes at some time in the future. An advance directive may take many forms, and is commonly referred to as a "living will." In a living will or advance directive for health care, you can describe the kind of life-sustaining treatment that you want – or do not want – if you enter a certain medical

state that makes you unable to communicate your wishes to your doctor. You must sign and date your living will for it to be valid. If you are unable to do so, someone else must sign it for you under your direction.

You may also write a Health Care Power of Attorney to designate a health care agent to make medical decisions on your behalf. Unlike a living will, you can specify that your Health Care Power of Attorney goes into effect before you enter an end-stage medical condition or become permanently unconscious.

For assistance in obtaining an attorney if you do not have a family attorney, or for further information, contact your local Area Agency on Aging, the Pennsylvania Bar Association Lawyer Referral Service, or The Senior LAW Helpline.

“Understanding Advance Directives; Living Wills and combined form, can be downloaded from this PA Department of Aging’s Web site, [www.aging.state.pa.us](http://www.aging.state.pa.us) or write to:

**PA Department of Aging**  
555 Walnut St., 5th Fl.  
Harrisburg, PA 17101-1919  
Or call (717) 783-1550

# Pennsylvania Alzheimer's Disease Planning Committee Public Comments Executive Summary

## COMMON TRENDS AND OVERLAPPING ISSUES

**Purpose:** *To provide all the workgroups with an overview of overlapping themes that were seen throughout the public comments that were submitted by online survey, public testimony, emails, and letters.*

### **Three Common Themes**

- Finance
- Dementia Friendly Communities
- Access to information

*Alzheimer's disease is the 6th leading cause of death in the United States overall, and the 5th leading cause of death for those age 65 and older. It is the only cause of death among the top 10 in America without a way to prevent it, cure it, or even slow its progression.*

### **Finance**

- More affordable options for persons with Alzheimer's disease and other dementias, caregivers, medical professionals, and researchers.
- More financial support for caregivers, medical professionals, home and community-based services, long-term care, training, education, and research.

### **Dementia Friendly Communities**

- Educating and encouraging communities to overcome the stigma surrounding a person living with Alzheimer's disease or other dementias.
- Communities working together to promote the safety of persons living with Alzheimer's disease and other dementias.
- Educating the public so that more people can understand Alzheimer's disease and other dementias to find ways to promote dementia friendly communities.
- Creating a system of recognition for organizations and communities that are promoting dementia friendly practices.

### **Access to Information**

- There needs to be a "clearinghouse" for individuals to find support to decipher legal situations, caregiver issues, and navigate financial and insurance support.
- Those suffering from the disease often stated how little they know about the disease, and often do not know where to turn to get more information.
- There needs to more public awareness to learn about the signs of Alzheimer's disease and related dementias to increase early detection and safer communities.

## PREVENTION AND OUTREACH WORKGROUP 1

**Purpose:** *To summarize the most frequent responses from the online survey, public testimonies, emails, and letters.*

### **Three Common Themes**

- Caregiver Support
- Training and Education
- Public Awareness

*In 2012, 15.4 million U.S. families and friends provided 17.5 billion hours of unpaid care to those with Alzheimer's and other dementias- Alzheimer's Association*

### **Caregiver Support**

- Lack of respite programs.
- It is unrealistic to think caregivers can get a break without significant in-home care assistance.
- Increase the number of caregiver support groups.
- Creating an up-to-date, county specific clearinghouse to give caregivers access to medical, legal, and stress management support.

### **Training and Education**

- Those living with Alzheimer's disease and other dementias need to be better informed about the disease.
- Instill educational partnerships between higher learning institutions and healthcare providers.
- Implementing creative ways to help educate and train caregivers to provide better in-home care for their loved ones.
- Establish communication strategies among healthcare providers and aging service providers to promote training and education.

### **Public Awareness**

- A better understanding of Alzheimer's disease and other dementias to prevent injuries, misunderstandings and altercations.
- Informing the public to be able to identify the signs of someone who may be suffering with Alzheimer's disease and other dementias. This increases the likelihood of appropriate interventions.
- Understand the hardships and emotional stress of those caring for a family member or friend living with Alzheimer's disease and other dementias.
- Provide awareness about elder abuse and financial exploitation.
- Address and reduce the stigma often associated with Alzheimer's disease and other dementias.

## HEALTHCARE DELIVERY & WORKFORCE WORKGROUP 2

### **Three Common Themes**

- Home and Community-Based Services
- Workforce Development
- Healthcare System Capacity

*“Finding community support is next to impossible, unless you have the immense savings for private pay.”*

### **Home and Community-Based Services**

- Many voiced a need to have safe, affordable care that allows those living with Alzheimer’s disease and other dementias to stay in the home longer to decrease the need for institutional care.
- Many families cannot afford to privately pay for in-home care.
- Increase the number of home and community-based services in rural areas.
- Expand and enhance adult day services, including operating hours, number of workers and transportation.
- It is difficult to get approved by Medicare for home and community-based services.

### **Workforce Development**

- Physicians and practitioners need to be more proactive in getting a diagnosis and providing information to the patient and loved ones about Alzheimer’s disease and other dementias.
- Cutting down on the inappropriate use of medication due to the lack of knowledge from practitioners.
- Increase training for primary care physicians to provide comprehensive care and case management for people with Alzheimer’s disease and other dementias.
- Training practitioners to better handle altercations when patients become combative to ensure patient safety.
- Since there is an increase in need, increase the number of geriatricians, although interest in the field is dwindling.

### **Healthcare System Capacity**

- Increase mandated staffing levels in memory care facilities.
- Increase staff to resident ratios in community-based and long-term care facilities.
- Increase the number of adult day, memory care, and skilled care facilities throughout the Commonwealth.
- Increase the number of trained practitioners, and encourage the recruitment and retention of skilled practitioners.

## RESEARCH AND METRICS WORKGROUP 3

### **Three Common Themes**

- Research and Studies
- Finance
- Federal & State Policy

*“In order to provide better services and care, we need improved data collection and more research funding.”*

*“The State plan should protect the livelihood of family caregivers and recognize the challenges*

### **Research and Studies**

- Increased research to fight and prevent this disease.
- More research of early onset Alzheimer’s disease.
- Increase research to improve treatment of Alzheimer’s for individuals with intellectual and developmental disorders.

### **Finance**

- Increase the lottery PACENET income criteria due to the cost of Alzheimer’s and dementia related medications.
- In order to provide better care and services there needs to be an increase in funding for research.
- Increased funding to improve training and education for healthcare practitioners.
- Develop programs to encourage individuals to plan financially to take care of loved ones or themselves if diagnosed with Alzheimer’s disease or other dementias.

### **Federal & State Policy**

- The state should work for stronger regulations for respite, community, and long-term care facilities.
- The state should require more training hours for aides in personal care homes, and increase the resident to aide ratio, to allow for better care and safer situations.
- The state needs to improve data collection process to better serve the population suffering with Alzheimer’s disease and other dementias.
- Reevaluate the use of Medicare for Alzheimer’s disease and other dementias, especially for Adult Day centers
- Formulate a process to combat elder financial exploitation, those suffering with Alzheimer’s disease and other dementias are greatly at risk.

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**NOTE: A SUMMARY OF ALL PUBLIC COMMENTS IS AVAILABLE BY EMAILING [ALZSTATEPLAN@PA.GOV](mailto:ALZSTATEPLAN@PA.GOV) OR BY CALLING 717-783-1550.**

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## Appendix F

### Acknowledgments

The Pennsylvania Alzheimer's Disease Planning Committee would like to thank all the individuals who made possible the submission of the Pennsylvania State Plan on Alzheimer's Disease and Related Disorders to Governor Tom Corbett.

The Committee expresses its thanks to our fellow Pennsylvanians who shared their experiences and suggestions during public regional meetings; advisors who provided guidance on key topics; consultants, and staff from the Governor's Office, Legislative offices and the Pennsylvania Department of Aging.<sup>i</sup>

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**Lynn Adams**, Social Worker and Certified Dementia Practitioner, Crawford County Care Center

**Judi Ahram**, President, Pennsylvania Adult Day Services Association

**James E. Anderson**, Executive Director, Pennsylvania Juvenile Court Judges' Commission

**Donald Anklum**, Elder Health Services

**Dr. Noel Ballentine**, Hershey Medical Center

**Dr. Arthur Barlow**, Retired Professor & Caregiver

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**Amy Bennett**, Arc of Centre County

**Joy Bodnar**, Director of Health Care Services, Foxdale Village

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**Dr. Ken Brubaker**, Chief Medical Officer, Pennsylvania Department of Aging

**Don Burkett**, Caregiver

**Janie Burstein-Boyle**, Caregiver

**Wendy Campbell**, President & CEO Alzheimer's Association, Delaware Valley Chapter

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**Susan Charnigo**, Caregiver

**Dr. Mahesh Chhabra**, M.D.

**Carrie Chiusano**, Caregiver

**Geri Cicchetti**, Caregiver

**Susan Coleman**, Caregiver

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**Lisa Davis**, Director, Pennsylvania Office of Rural Health

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**Terry Fink**, Manager, Tuscarora Senior Center

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**Nancy Florio**, Community Relations, Brookville Hospital

**Rosemary Frank**, Caregiver

**Deb Franzen**, Caregiver

**Carl Frels**, Caregiver

**Joseph French**, Caregiver

**Kathy Gillespie**, Director, Area Agency on Aging, Clearfield County

**Marie Goff**, Alzheimer's Association, Laurel Highland Chapter

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**Russell Goralczyk**, Caregiver

**Leslie Grenfell**, Executive Director, Area Agency on Aging of Southwest Pennsylvania

**Gwen** (No Last Name Provided), Caregiver

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**Bret Hart**, Kling Bros Insurance, LLC

**Jane Hauck**, Juniata Valley Senior Center

**Tina Hess**, Pennsylvania Adult Day Services Association

**Julia Ann High**, Caregiver

**Dr. Karen Hirschman**, University of Pennsylvania, School of Nursing

**Vicki Hoak**, CEO of Pennsylvania Homecare Association

**David Hoffman**, Attorney & Consultant

**JoAnn Holobinko RN**, Area Agency on Aging, Clearfield County

**Ruth Hood**, Program Director, Meals on Wheels, Pottstown

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**Kevin Jameson**, Caregiver

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**Coleen Kayden**, Pharmacist

**Deborah Kelly**, Visiting Nurse Association of Clarion Forest

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**Dr. Daniel Lago**, Central Regional Council on Aging

**Holly Lange**, Director, Philadelphia Corporation for Aging

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**Dr. Oscar Lopez**, Director, Alzheimer's Disease Research Center, University of Pittsburgh

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**Lottie Powell**, Caregiver

**Helen Sue Puskar-Frey**, Caregiver

**Donna Quinn**, Caregiver

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**Mary Renninger**, Caregiver

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**Carmen Torres**, Living with Alzheimer's disease

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**Wendy Campbell**, President & CEO, Alzheimer's Association, Delaware Valley Chapter

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**Jennifer Branstetter**, Director of Policy & Planning, Office of the Governor

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**Rebekah Ludwick**, Deputy Director for Policy and Planning and Special Projects Manager, Office of the Governor

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**Representative Mark Cohen**, Pennsylvania 202<sup>nd</sup> Legislative District

**Representative Pam DeLissio**, Pennsylvania 194<sup>th</sup> Legislative District

**Representative Hal English**, Pennsylvania 30<sup>th</sup> Legislative District

**Representative Marty Flynn**, Pennsylvania 113<sup>th</sup> Legislative District

**Representative Keith Greiner**, Pennsylvania 43<sup>rd</sup> Legislative District

**Representative Dan Miller**, Pennsylvania 42<sup>nd</sup> Legislative District

**Representative Donna Oberlander**, Pennsylvania 63<sup>rd</sup> Legislative District

**Representative Eddie Day Pashinski**, Pennsylvania 121<sup>st</sup> Legislative District

**Representative Katharine Watson**, Pennsylvania 144<sup>th</sup> Legislative District, Co-Chair of House Alzheimer's Caucus

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**Michael Deery**, for Senator LeAnna Washington

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**Arlen Larue**, for Representative Vanessa Brown

**Geoffrey Mock**, for Senator Shirley Kitchen

**Melissa Myers**, Committee Executive Director, Pennsylvania House Aging and Older Adult Services Committee

**Erin Raub**, Pennsylvania House Aging and Older Adult Services Committee

**April Rucker**, for Representative Florindo Fabrizio

**Geri Sarfert**, for Senator Bob Mensch

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**Amy Comarnitsky**, Aging Services Specialist

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Pittsburgh, Pennsylvania

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<sup>1</sup>The Committee utilized information gathered from sign in sheets and registration schedules and information in these lists was recorded as provided.