

## Coalition of New York State Alzheimer's Association Chapters 2014 Legislative Platform

# 10.6%

In New York, 10.6 percent of those aged 60 and over report that they are experiencing confusion or memory loss that is happening more often or is getting worse.

2011 Behavioral Risk Factor Surveillance System

# 48<sup>th</sup>

New York ranks 48th in the nation for support for family caregivers...

# 50<sup>th</sup>

...and 50th in the percentage of caregivers who usually or always get needed support.

AARP, The Commonwealth Fund and The SCAN Foundation Long-Term Care Services Scorecard

# \$283K to \$324K

In their lifetime, New York men lose an average of \$283,716 in wages, social security and pension earnings because of caregiving. The loss of income to women is \$324,044.

MetLife. (2011). *The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents; Caregivers In Crisis: New York State's Failure To Support Family Caregivers*, AARP New York, the Council of Senior Centers and Services of New York City, Inc., and the NYS Caregiving and Respite Coalition.

### BUDGET PRIORITY

#### *Invest \$5 million in Alzheimer outreach services and care coordination*

Dementia caregiving is a billion-dollar unpaid industry in New York State. More than one million New Yorkers provide daily unpaid care for someone with dementia totaling 1.14 billion hours of care annually. The market value of their unpaid care is more than \$14 billion. Yet, New York State's investment in dementia caregiver supports is paltry: \$559,000 in the SFY2014-15 executive budget, or a mere \$1.75 per person in New York diagnosed with Alzheimer's.

The toll of dementia care in New York is staggering:

- **65 percent** of caregivers report being late or leaving early from work, or having to take time off due to caregiving.
- **19 percent** left the workforce completely or took an early retirement.
- **13 percent** reduced their work hours from full- to part-time.

According to MetLife Mature Market Institute, caregiving costs American businesses \$33.6 billion annually. Not only does this impact a company's productivity and profitability, but it has a direct effect on tax revenues: caregivers in these situations earn less and have fewer discretionary resources at their disposal than if they were fully employed, leading to less income and consumption to tax. This "Bermuda Triangle" of reduced corporate productivity, incomes and tax base has a significantly negative effect on the New York State economy.

### THE ASK

- The Coalition respectfully requests \$5 million to support its initiatives under the Alzheimer's Community Assistance Program (AlzCAP). This would increase the state's per person investment to \$15.63.

### LEGISLATIVE PRIORITY

#### *Implement Priority Recommendations of the Alzheimer's Coordinating Council Plan*

New York State commissioned its state Alzheimer's plan in 2009. Under the direction of the executive branch, the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias, a team of aging experts and state officials, published one of the first state plans in the nation.

Four years later, few of its recommendations have been implemented. Department of Health Commissioner Nirav Shah's letter to doctors in November 2013 on the topic of early detection and diagnosis is an important first step.

It is critical for policymakers to ensure that the plan's recommendations are translated into actual policies. Only then will the burden on state budgets and families be reduced.

### THE ASK

The Coalition asks the legislature and Department of Health to implement the following recommendations from the plan:

- The Council's recommendation that a public education campaign be conducted to raise awareness about Alzheimer's disease (Section L).
- The Council's recommendation to include key topics related to Alzheimer's disease in training programs for health professionals (Section C).
- The Council's recommendation to educate employers about caregiving responsibilities and how they can be responsive to their employees through partnerships with trade organizations (Section B).

# \$1.5 billion

Cost of Alzheimer's caregiving to New York state employers.

Alzheimer's Association 2013 Alzheimer's Disease Facts and Figures; Caregiving in the U.S. 2009, MetLife Mature Market Study

### About the Coalition

The Coalition of New York State Alzheimer's Association Chapters, founded in 1980, advocates on behalf of the 320,000 Empire State residents living with Alzheimer's disease. It is New York's leader in meeting the needs of individuals with Alzheimer's disease and related dementias and those who care for them.

## LEGISLATIVE PRIORITY

### *Establish and institute comprehensive dementia training curriculum for facility staff statewide*

To best serve those with Alzheimer's, states should have a quality dementia care policy in place that ensures those with Alzheimer's receive care from knowledgeable professionals. All individuals employed in the delivery of care in residential, home, and adult day settings should be properly trained in dementia care using a common curriculum.

Historically, mandatory training laws have required a minimum number of hours of training, but have not consistently addressed the need for competency in dementia care. Training, particularly in the area of dementia care, varies based on healthcare setting. Addressing this need closes crucial gaps in the continuum of care for those in New York diagnosed with a form of dementia. This training is not only crucial to ensure quality care, but receives particular emphasis in reports published by the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias.

## THE ASK

- Pass **A.4467 (Gottfried)/S.1663 (Grisanti)**, which would require direct-care staff in adult care facilities to complete a training curriculum before being allowed to perform services without supervision. This legislation would also authorize the Department of Health to establish a workgroup to develop a uniform curriculum and best practices.
- Include dementia training under the uniform emergency preparedness training for first responders and local officials. The NYS Emergency Management Certification and Training Program (NYS-EMC) will certify participants for disaster response capabilities in counties throughout the state. The Coalition is requesting that dementia training be incorporated into this uniform emergency preparedness training. The Coalition can provide training guidelines to assist the State in developing curriculum.

## LEGISLATIVE PRIORITY

### *Conduct a referendum on bonds for Alzheimer's research*

Alzheimer's disease is a progressive brain disorder that damages and eventually destroys brain cells, leading to memory loss and changes in thinking and other brain functions. Ultimately, Alzheimer's is fatal, and currently, there is no cure. The cost of treating Alzheimer's in the U.S. is expected to increase from \$203 billion in 2013 to \$1.2 trillion by 2050.

While there is a neuroscience research effort underway to develop a new generation of more effective treatments, more funding is needed to support these efforts. Unfortunately, federal funding for research for Alzheimer's disease is extremely limited and currently New York State is not investing funding in the research efforts.

## THE ASK

- Pass **A.8140 (Lavine)/S.6284 (Carlucci)**, which would create a \$1 billion voter-approved general obligation state debt for the purpose of funding Alzheimer's research in the State of New York. This funding would provide support for research, would leverage private dollars and would create jobs for researchers in the Empire State.

## COALITION OF NEW YORK STATE ALZHEIMER'S ASSOCIATION CHAPTERS, INC.

### Our Mission

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.

### Our Vision

The Coalition of New York State Alzheimer's Association Chapters is a recognized leader to effect systems change through ensuring that every political door is open, every voice is heard, and every legislative initiative contains the Association's voice to benefit people with Alzheimer's disease, their families and caregivers.

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