

## New York State Coalition

# 2017 LEGISLATIVE AGENDA

***Alzheimer's disease is a public health crisis: nearly 400,000 New Yorkers currently have Alzheimer's disease and the Medicaid costs for caring for people with Alzheimer's reached \$4.2 billion in 2016.***

### **Increase Support for Alzheimer's Community Assistance Program in SFY 2017-18**

Thanks to a Legislative Act establishing the Alzheimer's Community Assistance Program (AlzCAP) more than 20 years ago, the Coalition of NYS Alzheimer's Association Chapters provides enhanced care, support and education services throughout New York State for persons with Alzheimer's disease or dementia and their caregivers. In 2015, Governor Cuomo made an historic investment in caregiver support to expand AlzCAP, a statutory contract with the NYS Department of Health (DOH), and related programs through the NYS Alzheimer's Caregiver Support Initiative, based on a study<sup>1</sup> that showed enhanced caregiver education allowed them to delay skilled nursing facility placement an additional 557 days. *Through AlzCAP, our efforts empower people to remain at home longer and reduce the Medicaid burden.*

#### **\$10 million for Public Education and Awareness**

Nationally, and in NYS, studies show people do not understand Alzheimer's and the importance of diagnosis and care planning. According to the 2015 Behavioral Risk Factor Surveillance System survey data, 11% of New Yorkers 45 and older report confusion or memory loss, but more than half of them have not spoken to a physician about it. To address this public health crisis, there is an urgent need to promote greater understanding of the early warning signs of Alzheimer's disease and the value of early diagnosis and planning.

In 2016, in coordination with DOH and pursuant to the NYS Alzheimer's Disease Plan<sup>2</sup>, the Coalition commenced a limited public awareness effort across the state in 2016. Results were immediate and staggering: *calls to the 24/7 Helpline increased 42%, attendance at education programs grew 34%, and just over a month of digital promotion produced nearly 100,000 hits to the Alzheimer's Association website.*

Increased public education and awareness drives constituents to seek services they so desperately need, but consistent, dedicated funding for public awareness does not exist. **The Coalition requests a \$10 million investment in public awareness through AlzCAP in SFY 2017-18 to launch a large-scale, culturally competent statewide public awareness campaign in coordination with DOH.**

#### **\$3.5 million for Program Delivery and Support**

The expansion of AlzCAP in 2015 enabled more New Yorkers than ever before to access Alzheimer's Association services critical to early diagnosis and expert planning. To best serve the growing number of those affected by Alzheimer's and dementia, more staff and programs are needed, particularly in New York City, where the population is denser. **The Coalition seeks an additional \$3.5 million for AlzCAP in SFY 2017-18 to grow services statewide.**

### **Improve Access to Assisted Living for Low-Income Seniors with Alzheimer's Disease and Dementia**

Currently, more than 45,000 New Yorkers live in assisted living and approximately 40% of them have some form of dementia. Consistent with industry best practices for those with dementia, the Coalition advocates for optimizing the most appropriate, but least restrictive, residential setting. Assisted living is preferred, where residents receive some cueing and support in a generally secure space, but live more independently than in a skilled nursing facility. Yet, assisted living is expensive. The existing NYS Assisted Living Program (ALP), the only assisted living option for low-income seniors, has limited capacity and is not easily accessible. In its current form, ALP does not offer a comprehensive long-term care solution for NY's aging population.

<sup>1</sup> Improving caregiver well-being delays nursing home placement of patients with Alzheimer's disease. *Neurology*, 2006. Mittelman MS, Haley, Clay, Roth.

<sup>2</sup> 2015 Report of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias to Governor Andrew M. Cuomo and the New York State Legislature

## **Improve Access to Assisted Living for Low-Income Seniors with Alzheimer's Disease and Dementia (continued)**

### **Create Pilot Project to Offer Voucher Payments to Private-pay Assisted Living Residences to Avoid Discharge**

Seniors with dementia who can no longer afford their private-pay rate while living in an assisted living residence (ALR) usually have no other option than to go on Medicaid, resulting in a move to a skilled nursing facility at considerable cost to NYS. This option is contrary to longstanding public policy to keep people with dementia in a familiar, less restrictive setting. **The Coalition supports creating a pilot project to provide voucher payments to private-pay ALRs to retain spend-down residents and mitigate the State's Medicaid burden.**

### **Increase Assisted Living Program Capacity to Accommodate the Growing Alzheimer's Population**

Lower income seniors who would like to transition to assisted living are often ineligible based on ability to pay. While there are approximately 10,000 ALP beds authorized, they are inconsistently and insufficiently apportioned throughout the state. **The Coalition advocates expanding the Assisted Living Program to allow greater access for low-income New Yorkers with dementia to reduce unnecessary, costly nursing home admissions.**

## **Protect New Yorkers with Dementia from Financial Exploitation**

More than 60% of financial exploitation crimes against seniors are perpetrated by someone the victim knows and should be able to trust family, friends, caregivers and professionals. These unscrupulous criminals take advantage of their access to the financial accounts of the most vulnerable. According to the 2016 NYS Office of Children and Family Services *Cost of Financial Exploitation Study*, more than one-third of those exploited exhibited signs of dementia. Cases have skyrocketed 35% in the last five years, but implementing changes to our financial systems to safeguard the potential risks could have a significant impact on halting this frightening and devastating trend.

### **Empower Banks to Prevent Financial Exploitation and Establish Training Guidelines**

**The Coalition supports legislation to protect seniors from financial exploitation through improved dementia training including S1093 (Valesky)/A6099 (Lupardo) and A6395 (Lupardo), to develop training guidelines.**

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## **Coalition Board and Staff**

**Elizabeth Smith-Boivin**

*President*

**Teresa Galbier**

*Treasurer*

**Douglas Davidson**

*Secretary*

**Catherine James**

**Christopher Smith**

**David Sobel**

**Beth Kallmyer**

**Jane Ginsburg**

*Executive Director*

[jginsburg@alz.org](mailto:jginsburg@alz.org)

518.867.4999 x208

## **Coalition Chapters**

**Central New York**

441 W. Kirkpatrick St.

Syracuse, NY 13204

315.472.4201

Catherine James, CEO

**Hudson Valley**

2900 Westchester Ave., Suite 306

Purchase, NY 10577-2551

845.471.2655

David Sobel, President/CEO

**Long Island**

425 Broadhollow Rd., Ste. 307

Melville, NY 11747

631.629.6950

Douglas Davidson, Executive Director

**New York City**

60 East 42<sup>nd</sup> Street, Suite 2240

New York, NY 10165

646.793.3523

Christopher Smith, Executive Director

**Northeastern New York**

4 Pine West Plaza, Ste. 405

Albany, NY 12205

518.867.4999

Elizabeth Smith-Boivin,

Executive Director, CEO

**Rochester and Finger Lakes**

435 E. Henrietta Rd.

Rochester, NY 14620

585.760.5400

Teresa Galbier, President/CEO

**Western New York**

2805 Wehrle Dr., Ste. 6

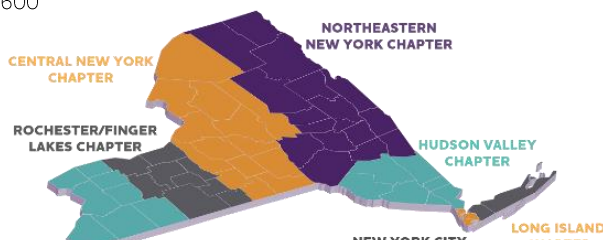
Williamsville, NY 14221

716.626.0600

*THE ALZHEIMER'S ASSOCIATION, NEW YORK STATE COALITION is the leading statewide organization advocating for all New Yorkers affected by Alzheimer's disease and dementia. We seek 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. Aligned with the National Alzheimer's Association, our vision is a world without Alzheimer's.*

*FOR MORE THAN 30 YEARS, Coalition chapters have offered in-person support in every county of New York, including care consultations, consumer and professional educational programs, a 24-hour Helpline, safety services and support groups.*

*THROUGH ROBUST STATEWIDE ADVOCACY AND EDUCATION, the Coalition advances public policy, provides and enhances care and support, and increases concern and awareness of Alzheimer's disease and dementia.*



**800.272.3900**

24/7 Free Helpline Available  
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**alz.nys.org**