



advocate's guide

Alzheimer's Association Advocacy Forum

Washington Marriott Wardman Park

March 23-25

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Dear Alzheimer's Advocate:

Welcome to the 2015 Alzheimer's Association Advocacy Forum. Your participation in this important event demonstrates your commitment to conquering this devastating disease. Whether this is your first time attending the Forum or you've participated in previous years, we're delighted you have decided to be a part of this advocacy movement.

Over its 27 year history the Forum and its attendees have played a major role in the achievement of major policy victories, from passage of the Family Caregiver Support Program, the establishment of the National Alzheimer's Plan, increases in funding for Alzheimer's research, education, outreach and caregiver support and, just this past year, passage of the Alzheimer's Accountability Act.

As the world's leading Alzheimer's advocacy organization the Association fights for critical research, prevention and care initiatives at the federal, state and local levels to ensure that families affected by Alzheimer's are not forgotten by our government. And **YOU** are the key to achieving our vision of a world without Alzheimer's.

This Advocate's Guide will serve as a year-round reference as you interact with members of Congress and other elected officials. We hope you find this guide easy to access and we encourage you to share it with your friends, neighbors, and others who wish to join our movement.

In the following pages you'll find background information on our issues, resources for accessing information on the web and mobile devices, suggestions for content to share on your social networks, statistics and other information on Alzheimer's disease. We hope this information is helpful to you, but please remember that **YOU** are the most important part of our program. While tips, tactics and statistics are important, they aren't nearly as relevant as your personal experiences with Alzheimer's. Your personal story is the most effective way to make an impact on elected officials and their staff. Therefore, in this guide you will also find tips on how to deliver that story to have the greatest impact.

We thank you for your dedication to making Alzheimer's a national priority.

Sincerely,

Your Alzheimer's Advocacy Team

Getting Started

Advocate Resources	5
Changing the Trajectory of Alzheimer's Disease	6
Public Policy Victories	7
Alzheimer's Advocacy Reporting & Trends	8

Meeting Elected Officials

Tips for a Good Meeting	9
Meeting Checklist	10

Our Message

2015 Federal Priorities	11
Fiscal Year 2016 Research Funding Fact Sheet	12
Increase the Commitment to Alzheimer's Research	13
The HOPE for Alzheimer's Act Fact Sheet	15
The HOPE for Alzheimer's Act Talking Points	16
The Alzheimer's Accountability Act Fact Sheet	18
2015 State Priorities	19
State Policy 101	20

Next Steps

Sample Follow-Up Letter	24
Year-Round Advocacy	25
What to Do After Forum	28
The Alzheimer's Impact Movement	29
Congressional Calendar	30

Advocate Resources



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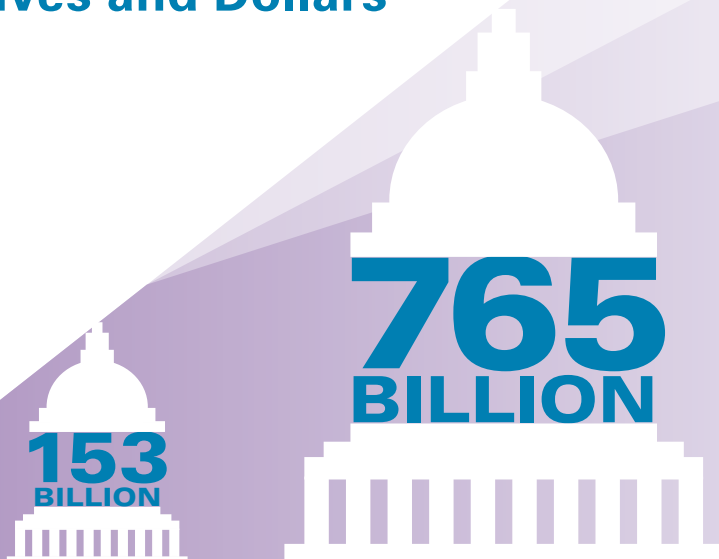


STATE & LOCAL

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alz.org/stateplans

Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars

Medicare & Medicaid will spend \$153 billion on Alzheimer's in 2015 and \$765 billion in 2050.



In 2015, nearly 1 in 5 (18%) Medicare dollars will be spent on someone with Alzheimer's.



In 2050, nearly 1 in 3 (31%) Medicare dollars will be spent on someone with Alzheimer's.

DELAYED ONSET

If we develop a treatment by 2025 that delays the onset of Alzheimer's by just five years, then:

5.7 MILLION

people expected to develop Alzheimer's would not in 2050.



Families would save \$87 billion in 2050.



In total, America would save \$367 billion in 2050.



If we achieve the National Alzheimer's Plan 2025 goal, there will be a total savings of \$220 billion over the first five years.

A federal research investment of **\$2 billion a year**, as suggested by the scientific community, would be **recouped in the first three years** after a treatment became available.



To see the complete report, visit alz.org/trajectory.

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TAKING ACTION

The Advocacy Forum has a successful history of bringing people together to tackle the challenge of Alzheimer's disease. Ambassadors and advocates, together with the Association, are responsible for the following victories.

PUBLIC POLICY VICTORIES

2011

The National Alzheimer's Project Act signed into law

2013

\$40 million from the NIH Directors budget for additional Alzheimer's research

2015

What's next?

2012

The first-ever National Alzheimer's Plan released along with an additional \$50 million in federal research funding

2014

\$122 million for Alzheimer's research, education, outreach and support. Passage of Alzheimer's Accountability Act

Alzheimer's Advocacy Reporting & Trends

Become a part of our online advocate community at alzadvocacy.org (AART). Join other dedicated Alzheimer's advocates who are changing the future of Alzheimer's with their investment of time today.

Interact with our core group of advocates who keep Alzheimer's issues on the minds of those in Congress and in state capitols around the country.



Tell us about your actions and request follow-up activity



Interact with Alzheimer's Congressional Team members



See activities and what's going on around the country



Complete projects and earn recognition for your efforts



Access your account via any mobile device



Learn about your elected officials

Tips for a Good Legislative Visit

How to communicate with legislators and other officials

PLAN YOUR PITCH

Planning is everything. Take the time to develop, rework, and refine your stance in advance. In other words, be prepared.



LISTEN

Let the official express his or her point of view.

BE COURTEOUS

Even if they vehemently disagree with your cause, they may support our future efforts. It's important not to burn any bridges.



BE BRIEF

Get in and out of an official's office quickly. Show that you know the value of his or her time.

SIMPLICITY

Keep it simple! Don't be too technical, too detailed, too complex or too oblique. Get to the point, cover the basics and make sure the official understands your main point.



KEEP YOUR GROUP SMALL

An unwieldy group can make everyone uncomfortable, distract from your message and waste valuable time getting set up. Make certain that the group has already decided on a spokesperson and stick with that decision.

NEVER TELL A LIE

Your reputation is everything. You lose your credibility permanently if you lie. If you don't know the answer to a question, tell them you don't know, but you'll find out and then follow up. Be sure to let the D.C. Public Policy office know so that we can help.

DON'T FORGET TO CLOSE

Always ask for the official's vote or support. Remember to pause and wait for a response.

THANK YOU

Remember to call/send a note to your elected official to remind them of your visit, and thank them for their time and support. An example is contained at the end of this section.



Please make sure to enter your meeting report at www.alzadvocacy.com

Legislative Meeting Checklist

Roles and Assignments

- Who is responsible for bringing materials to the meeting?
Ex. The leave behind packet, printed materials
- Who is going to handle introductions?
Ex. Who we are, why we're here
- Who is going to discuss the state of Alzheimer's?
Ex. Facts & Figures, visual aids and materials
- Who is going to talk about the first issue/legislation and tell their story?
- Who is going to make the first/primary "ask"?
- Who is going to talk about the second issue/legislation and tell their story?*
- Who is going to make the secondary "ask"?*
- Who is going to conclude the meeting?



*if applicable

On Site Pre-meeting

- Have the meeting time and location been confirmed?
- Do all attendees have the legislative office's contact information?
- Are all meeting attendees present and accounted for?

Post-meeting

- Who will submit the meeting report to
www.alzadvocacy.com?
- Who will follow-up with the legislative office?
Ex. Provide answers to pending questions, submit additional materials
- Who will update/debrief meeting participants and provide next steps?

FEDERAL PRIORITIES 2015

Alzheimer's disease is a growing crisis for our families and the economy. The federal government must address the challenges the disease poses and take bold action to confront this epidemic now.

1. Increase the commitment to Alzheimer's research

Alzheimer's is the most expensive disease in America. Nearly one in every five Medicare dollars is spent on someone with Alzheimer's or another dementia, and by 2050, it will be nearly one in every three dollars. Between now and 2050, caring for people with Alzheimer's will cost our country \$20.8 trillion. If we meet the goal of the National Alzheimer's Plan to have an Alzheimer's treatment by 2025, Medicare spending would be reduced on those with the disease by nearly 25 percent in 2050 alone – and the federal government would recoup its research investment within three years.

While Congress has recently provided additional funding for Alzheimer's research at the NIH – including an additional \$25 million in fiscal year 2015 – the chronic underinvestment in Alzheimer's research persists and it continues to fall far short of what researchers say is needed to reach the 2025 goal. For every \$100 that the NIH spends on Alzheimer's research, Medicare and Medicaid spend over \$26,000 caring for those with the disease. Congress must continue its commitment to the fight against Alzheimer's by **increasing funding for research by \$300 million** in fiscal year 2016.

2. Improve access to care planning

To ensure high quality medical care and better outcomes for individuals with Alzheimer's, the disease must be diagnosed, care must be planned, and the diagnosis must be noted in the individual's medical record. Studies also suggest that an early diagnosis and care planning improve a caregiver's long-term health. Yet, less than half of seniors who have been diagnosed with Alzheimer's disease, or their caregivers, are aware of the diagnosis. One reason is the lack of time and resources available to doctors to discuss treatment options and support services with newly-diagnosed individuals and their caregivers.

Consistent with the National Alzheimer's Plan's call for timely diagnosis and education for newly-diagnosed individuals, **the *Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act*** would provide Medicare coverage for comprehensive care planning services – for both the individual and his/her caregiver – following a dementia diagnosis. Providers would be required to document the diagnosis and care planning services in the individual's medical record. The federal government would conduct outreach to providers to educate them about the new benefit.

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Fiscal Year 2016 Alzheimer's Research Funding

The escalating Alzheimer's epidemic has profound implications for government budgets – in addition to its devastating impact on families.

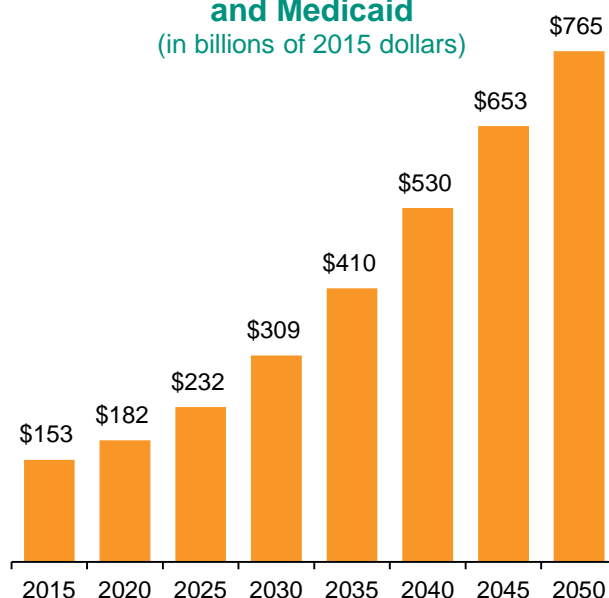
- Alzheimer's is the most expensive disease in America, costing more than heart disease and cancer.
- In 2015, caring for people with Alzheimer's and other dementias will cost the United States an estimated \$226 billion. Cumulatively between now and 2050, it will cost \$20.8 trillion, with more than half of the cost being borne by Medicare.
- Nearly one in every five dollars of Medicare spending is spent on people with Alzheimer's and other dementias.

Despite the growing burden of the disease, the chronic underinvestment in Alzheimer's research persists.

- For fiscal year 2015, Congress provided an additional \$25 million for Alzheimer's research at the National Institutes of Health (NIH).
- Even with the recent increases in funding, however, the NIH is expected to spend only \$586 million on Alzheimer's research in 2015.
- This means that for every \$26,000 Medicare and Medicaid spend caring for people with Alzheimer's, the NIH spends only \$100 on Alzheimer's research.

Alzheimer's Costs to Medicare and Medicaid

(in billions of 2015 dollars)



Congressional action is needed to stay on the path to discovering scientific breakthroughs.

- In 2012, an expert panel of scientists concluded that a ramp up to \$2 billion in annual Alzheimer's research funding is necessary to achieve breakthroughs in developing preventions and effective treatments for Alzheimer's by 2025 – the goal established in the National Alzheimer's Plan.
- To achieve this, the next step is for Congress to provide an additional \$300 million in NIH Alzheimer's research funding as part of the fiscal year 2016 appropriations process.

Increase the commitment to Alzheimer's research

Background and Congressional Talking Points

March 2015

Request: Please show your support for Alzheimer's research by sending a letter to the Chair and Ranking Member of the Appropriations Committee supporting a \$300 million increase for Alzheimer's research activities.

Background:

Congress unanimously passed the bipartisan National Alzheimer's Project Act (P.L. 111-375) in 2010. The law requires the Secretary of the Department of Health and Human Services (HHS) to create and annually update a National Alzheimer's Plan to overcome the disease. The Plan, reported to Congress annually, must include recommendations for priority actions both to improve health outcomes for individuals and to lower costs to families and government programs.

In 2012, an expert panel of scientists concluded that to achieve the necessary breakthroughs in developing preventions and effective treatments for Alzheimer's by 2025 – the goal established in the National Alzheimer's Plan – a rapid ramp up to \$2 billion in annual research funding is necessary. To continue that ramp up, Congress must provide an additional \$300 million in Alzheimer's research funding as part of the fiscal year 2016 appropriations process.

Talking Points:

- According to an NIA-funded study in the *New England Journal of Medicine*, Alzheimer's is the most expensive disease in America.
- This year the cost of caring for those with Alzheimer's disease will be an estimated \$226B, with \$153B of that amount paid for by Medicare and Medicaid. This annual expense is set to increase rapidly to \$1.1T by mid-century.
- However, a treatment that simply delayed onset of Alzheimer's by five years would lower Medicare spending on those with the disease by a quarter in 2050.
- By making Alzheimer's a national priority, we can create the same successes that we have been able to achieve in other diseases that have been prioritized by the federal government. Leadership from the federal government has helped lower the number of deaths from other major diseases such as HIV/AIDS, many cancers, heart disease, and stroke.
- Recognizing the growing Alzheimer's crisis, Congress unanimously passed the bipartisan National Alzheimer's Project Act (NAPA), calling for the creation of a National Alzheimer's Plan.
- The National Plan has resulted in some notable accomplishments, including NIH creating a blueprint for Alzheimer's research. However, for the progress this disease requires, scientists need the necessary funds to carry out the blueprint.
- For every \$100 that the National Institutes of Health (NIH) spends on Alzheimer's research, Medicare and Medicaid spend over \$26,000 caring for those with the disease.
- Congress must continue its commitment to the fight against Alzheimer's by increasing funding for Alzheimer's research by \$300 million in fiscal year 2016.

Share Your Experience:

- *Tell your personal story. Congress continues to be focused on deficit reduction and reducing government spending. If you are comfortable doing so, please share your experience with the economic pressures created by the disease including unnecessary hospitalizations, out-of-pocket costs, and complications with other conditions.*

Frequently Asked Questions – For Use During Congressional Meetings

During the course of your meetings with members of Congress and their staffs, you may encounter some common questions regarding the National Alzheimer's Plan. We have addressed some of these common questions below.

Is this a programmatic request? The deadline for appropriations letters has passed.

Suggested Response:

- This is not a programmatic request; it is a letter of support for an increase in the overall level of funding for Alzheimer's at NIH. Letters of support can be sent up until the Labor-HHS Appropriations bill is passed.

NIH already receives funding for Alzheimer's; why the additional \$300 million?

Suggested Response:

- The National Alzheimer's Plan – mandated by Congress – set forth a bold agenda to prevent and effectively treat Alzheimer's disease by 2025. The Plan outlined action steps that the federal government needs to take to meet that goal. This funding will be used to implement those action steps.
- Alzheimer's is the only one of the leading causes of death in the U.S. that cannot be prevented, cured, or even slowed. The primary reason this remains true is that we have put toward Alzheimer's only a fraction of what's been applied over time to address other major diseases. This underfunding of Alzheimer's research cannot be justified by either scientific opportunity or disease burden.
- The burden of Alzheimer's disease (both financial and in terms of human lives) will increase rapidly in the future, yet NIH is spending only \$586 million this year on research.
- If a treatment became available in 2025 that delayed onset of Alzheimer's for five years (a treatment similar to anti-cholesterol drugs), savings would be seen almost immediately, with Medicare and Medicaid saving \$121 billion over just the first five years.

Congress doesn't earmark money by disease. Why should Alzheimer's be different?

Suggested Response:

- Additional funding is in the NIH budget because their scientists have determined that additional research on Alzheimer's is a priority. Congress isn't earmarking funds for NIH, it is simply being asked to support the priorities identified by the scientists.
- The Alzheimer's Association agrees that Congress should not pick the specific research projects to be funded -- that is a job for scientists, not politicians.
- However, Congress does have a responsibility to direct resources to solve the most serious problems. By every objective standard (whether cost to Medicare/Medicaid, families caring for individuals with Alzheimer's, or mortality rate), Alzheimer's is one of our most serious health problems – and it will only get worse as the Baby Boomer generation ages.

The Member does not send letters to the Appropriations Committee.

Suggested Response:

- As our Representative in Congress we are requesting that you tell us whether or not you support this funding and to make your position public. Do you support the need for this funding?
- If you are not ready to take a position at this moment, we certainly respect that. Can we and other constituents meet with you again in the district within the next several weeks after you have had time to carefully review the issue and reach a decision?

(There will be further discussion at the breakout sessions on what to do if the Representative is not willing to send a letter.)

NOTE: If your Member of Congress or their staff asks you a question you do not know the answer to, that is not a problem. Do not feel any pressure to provide an answer. Please simply ask them to contact a member of the Alzheimer's Association's Federal Affairs Team at 202.393.7737. Please also indicate the interaction on your congressional report form so a member of the Federal Affairs team can follow-up with that office.

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HOPE for Alzheimer's Act

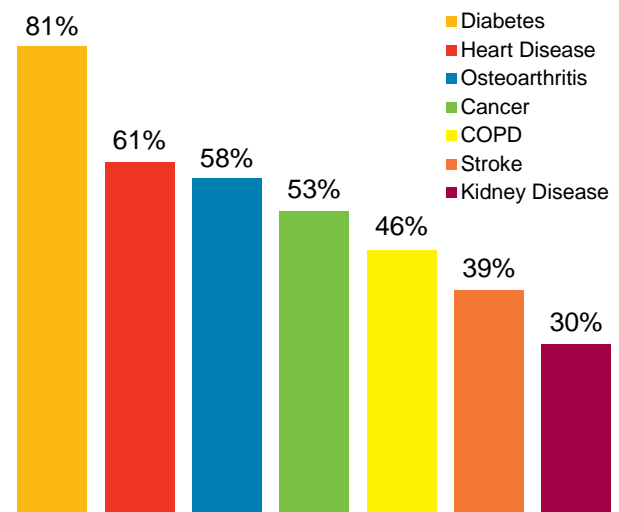
Following a diagnosis of Alzheimer's, care planning is crucial to improving outcomes for individuals and caregivers.

- Care planning allows newly-diagnosed individuals and their caregivers to learn about medical and non-medical treatments, clinical trials and support services available in the community.
- Having this information soon after a diagnosis improves the quality of medical care an individual receives and results in a higher quality of life. Studies suggest that care planning can improve the long-term health of caregivers as well.

Documentation in the medical record is critical for coordinating care and managing other chronic conditions.

- Alzheimer's complicates the management of other chronic conditions – and as a consequence increases costs.
 - For example, a senior with diabetes and Alzheimer's costs Medicare 81 percent more than a senior who has diabetes but no Alzheimer's.
 - Seniors with Alzheimer's have more than three times as many hospital stays as other seniors – stays often resulting from a condition complicated by Alzheimer's.
- Documenting the diagnosis in the medical record makes all treating physicians aware of the diagnosis, enabling them to better manage the individual's health care.

Higher Medicare Costs Due to Alzheimer's



Consistent with the *National Plan to Address Alzheimer's Disease, the Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act* would:

- Provide Medicare coverage for comprehensive care planning services following a dementia diagnosis; the services would be available to both the diagnosed individual and his/her caregiver.
- Ensure that documentation of a dementia diagnosis and any care planning provided is included in an individual's medical record.
- Require the Department of Health and Human Services to educate providers about the new benefit and to identify any barriers individuals face in accessing care planning.

THE HEALTH OUTCOMES, PLANNING, AND EDUCATION (HOPE) FOR ALZHEIMER'S ACT

Background and Congressional Talking Points

March 2015

Request: Please cosponsor the HOPE for Alzheimer's Act, which will ensure Medicare beneficiaries newly-diagnosed with Alzheimer's disease and their families receive comprehensive care planning services.

Background:

The Alzheimer's Association strongly supports the bipartisan HOPE for Alzheimer's Act, which was reintroduced in the 114th Congress by Senators Debbie Stabenow (D-MI), Susan Collins (R-ME), Shelley Moore Capito (R-WV), Edward Markey (D-MA) and Representatives Chris Smith (R-NJ-4), Paul Tonko (D-NY-20), Peter Roskam (R-IL-6), Earl Blumenauer (D-OR-3).

Following a diagnosis of Alzheimer's disease, comprehensive care planning is crucial to improving outcomes:

- Medicare already provides coverage of Alzheimer's disease diagnostic services.
- After diagnosis, health care professionals need time and resources to discuss both the diagnosis and also treatment and support options with patients and their families.
- Care planning services following a diagnosis of Alzheimer's disease can provide much-needed information on treatments, services and supports that may help improve or maintain quality-of-life for the individual, their family and caregivers.

The HOPE for Alzheimer's Act builds upon existing Medicare coverage of a diagnosis and would provide the time doctors say they need to talk to their patients about an Alzheimer's diagnosis:

- Provides coverage for comprehensive care planning services to Medicare beneficiaries and their caregivers following a diagnosis of Alzheimer's disease;
- Requires documentation of the diagnosis and care planning services in the beneficiary's medical record to aid in the coordination of care and management of other conditions.

The HOPE for Alzheimer's Act takes steps to ensure access to care planning services:

- Requires the Secretary of Health and Human Services (HHS) to conduct provider outreach to inform practitioners about the services under the HOPE benefit; and
- Requires HHS to report to Congress and the Advisory Council on Alzheimer's Research, Care, and Services on barriers beneficiaries face in accessing the services, as well as recommendations to eliminate those barriers.

The HOPE for Alzheimer's Act takes steps to implement the National Plan to Address Alzheimer's Disease by:

- Educating and supporting individuals with Alzheimer's disease and their families upon diagnosis;
- Educating health care providers; and
- Enhancing assistance for people with Alzheimer's disease and their caregivers to prepare for care needs.

Share Your Experience

- *If you and your family experienced challenges in obtaining assistance following a diagnosis, please share your story with your Member of Congress or their staff.*
- *Share a story highlighting how access to care planning and information about the disease would have benefited you and your family.*

Frequently Asked Questions – For use during your Congressional meetings

What changes were made to the bill since the 113th Congress?

Suggested Response:

- The bill has been modified to take into account a number of developments since it was introduced in 2010, including the passage of the National Alzheimer's Project Act (NAPA) and the Affordable Care Act (ACA).
- Because a diagnostic evaluation is already covered, the bill no longer provides coverage for a diagnosis as part of a package of services.
- The bill requires stakeholder input on the scope and requirements of the care planning services.
- The bill requires a provider outreach campaign to educate practitioners about the benefit in an effort to ensure broad access to the services by beneficiaries.
- For additional technical changes, a member of the Alzheimer's Association's Federal Affairs team would be happy to walk you through improvements to the bill.

What is the budgetary impact of the HOPE Act?

Suggested Response:

- The CBO has not yet scored this legislation, and we do not have a cost estimate for the bill. The Alzheimer's Association will continue to work with the bill's sponsors and committees of jurisdiction to determine the potential impact on federal spending.
- However, we know that participation in certain community support programs -- which people would have greater awareness of if there was care planning -- can, for instance, delay placement in nursing homes.
- Furthermore, the HOPE Act would allow for better care coordination and management of other chronic conditions, which could reduce costs.
- For example, we know that Alzheimer's disease complicates the treatment of other chronic conditions, such as heart disease and diabetes. In fact, take the case of diabetes: a senior with diabetes and Alzheimer's costs Medicare 81 percent more than a senior with diabetes but no Alzheimer's.
- In addition to providing care planning services, the HOPE Act requires medical record documentation of the diagnosis and the care plan -- both of which are critical for care coordination and chronic disease management, which can help reduce complications and thus costs.

Why is provider outreach necessary?

Suggested Response:

- Currently, there is no treatment for Alzheimer's disease. Studies show that one reason doctors don't disclose an Alzheimer's diagnosis to their patients is due to a lack of an available treatment.
- Outreach on the availability and elements of the HOPE benefit will educate providers on what *can* be done after a diagnosis, as well as give assurance that they will be reimbursed for their time in providing the benefit, which could help ensure access to these critical services and lead to more patients being informed of their diagnosis.

Are these services already covered by Medicare?

Suggested Response:

- Not in a comprehensive way that provides complete information for beneficiaries and providers.
- Current coverage for care planning falls short of the type of comprehensive planning required for providers and caregivers to care for patients and families following an Alzheimer's diagnosis.

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Alzheimer's Accountability Act

What is the Alzheimer's Accountability Act and what does it require?

- The Alzheimer's Accountability Act is bipartisan legislation enacted as part of the fiscal year 2015 omnibus appropriations bill (Public Law 113-235).
- The law requires the scientists at the National Institutes of Health (NIH) to submit an annual Alzheimer's research budget proposal directly to Congress, thus bypassing the usual bureaucratic budget procedures.
- This budget proposal – officially known as a “Professional Judgment Budget” – will specify the resources that scientists need to reach the National Alzheimer's Plan goal of preventing and effectively treating Alzheimer's disease by 2025.

What does the Alzheimer's Accountability Act have to do with the *National Plan to Address Alzheimer's Disease*?

- The National Plan, released in May 2012, sets a goal of preventing and effectively treating Alzheimer's disease by 2025. To reach that goal, the NIH has established research milestones and timelines, but has not specified funding levels.
- The Alzheimer's Accountability Act requires the NIH to develop an Alzheimer's research budget each year through 2025, specifying the level of investment scientists believe is needed to achieve the milestones and 2025 goal.

Alzheimer's Research Milestones

To achieve the National Alzheimer's Plan's goal of preventing and effectively treating Alzheimer's by 2025, the NIH has established 41 milestones across 10 areas of research, including drug development, biomarkers, non-pharmacological interventions, and clinical trial recruitment.

Following the NIH Alzheimer's Disease Research Summit in February 2015, the NIH began updating and revising the milestones. An expert workgroup convened by the Alzheimer's Association has made recommendations on improving the milestones, addressing gaps, and creating additional milestones to increase the likelihood of achieving success. The workgroup's recommendations are available at alzheimersanddementia.com.

Why is the Alzheimer's Accountability Act important in increasing Alzheimer's research funding?

- Given the financial burden Alzheimer's puts on Medicare and Medicaid – \$153 billion in 2015, growing to a projected \$765 billion in 2050 – a commitment to Alzheimer's research today will yield savings tomorrow.
- The Alzheimer's Accountability Act ensures Congress hears directly from scientists what they will need to meet the nation's goal and equips Congress with the best information to determine necessary Alzheimer's research funding levels each year through 2025.

STATE PRIORITIES 2015

Alzheimer's disease is a pivotal public health issue, and state governments stand on the front line. States must take bold action to confront this epidemic now.

1. Develop and implement a comprehensive state Alzheimer's disease plan

alz.org/stateplans

State Alzheimer's Disease Plans create the infrastructure and accountability necessary to confront the sweeping economic and social impact of this disease. By creating a formal state governmental process and bringing together essential stakeholders – such as state agency officials, legislators, care providers, family caregivers, and people with Alzheimer's – critical issues can be identified, solutions can be explored, and a roadmap can be constructed to guide a state's development into a dementia-capable state. Every state must develop a State Alzheimer's Disease Plan. In those states with a published plan, efforts must be undertaken to ensure that the plan's recommendations are fully implemented and that the plan is kept up-to-date to account for current needs and recent developments.

2. Adopt uniform adult guardianship legislation

alz.org/guardianship

States must ensure that their policies on advance directives and care planning reduce the complexity of end-of-life decision-making. One important step is to enact the budget-neutral Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (UAGPPJA), as approved by the Uniform Law Commission. UAGPPJA establishes a framework for courts in different states to communicate about adult guardianship cases and thus makes the resolution of multi-state jurisdictional issues easier for family members.

3. Improve dementia training

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 and non-residential settings should be properly trained in dementia care. States must have adequate dementia-training laws in place across the care continuum that include provisions ensuring that individuals achieve and demonstrate competency.

4. Increase state based surveillance through the BRFSS

alz.org/publichealth

Obtaining a more definitive picture of Alzheimer's is essential to any successful strategy to address the disease. Work by the Centers for Disease Control and Prevention (CDC) enables states to collect data on the impact of cognitive decline and Alzheimer's caregiving using the existing state Behavioral Risk Factor Surveillance System (BRFSS). Two modules are available: a Cognitive Module and a Caregiver Module. States should include these two modules in their state BRFSS to provide a better understanding of – and to identify opportunities for reducing – the impact of this devastating disease.

State Policy 101

State policy is vital to the work Association Chapters do to meet the needs of individuals living with Alzheimer's and their families. State officials determine regulatory and statutory standards for dementia training, control spending on state respite care dollars (which affects access to those services), designate spending for state long-term care services, and control Medicaid spending, and in some cases, eligibility and scope of benefits - all of which can have a direct effect on families for whom the Association provides care and support.

Important facts about state legislators, how to work with them and what actions to take include:

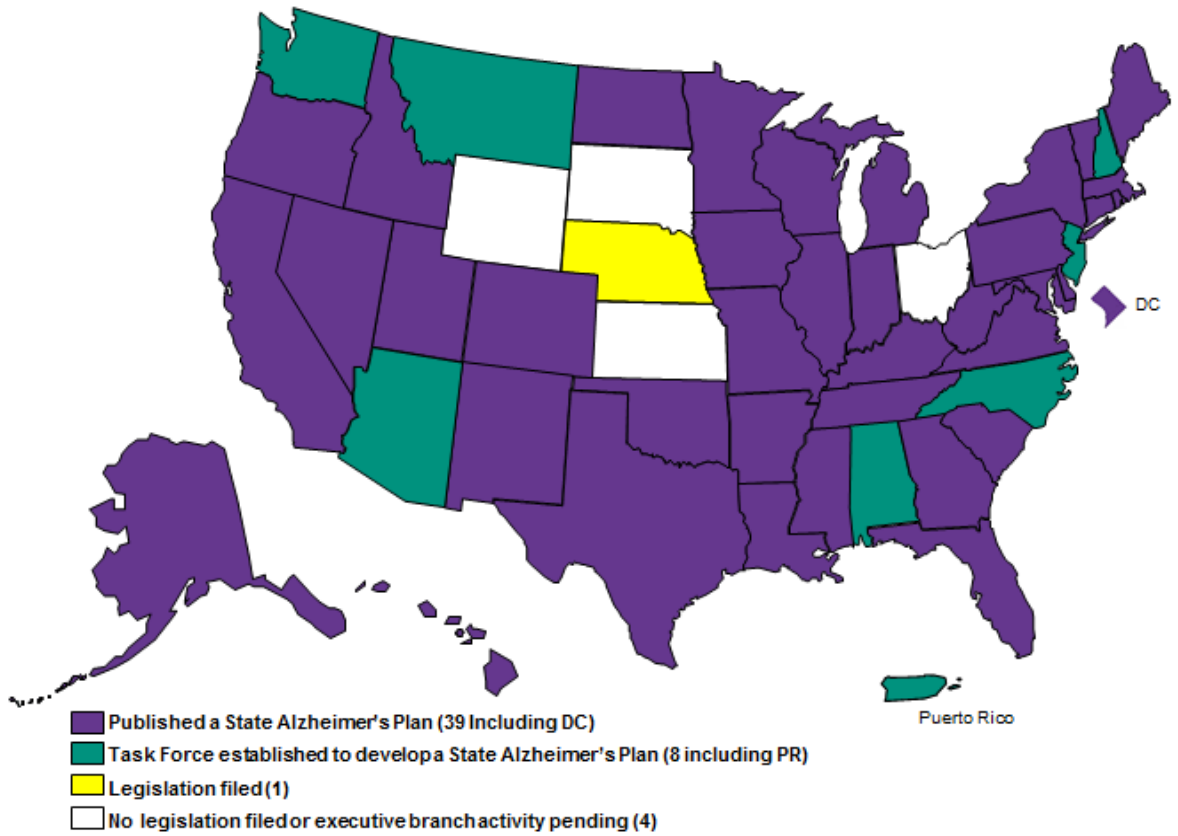
- Every state except one has a *bi-cameral legislature* composed of a House (or Assembly) and a Senate. The one exception is Nebraska, which has a unicameral legislature with just one Chamber.
- The lengths of *legislative sessions* are different in each state. Most states begin their sessions in January and end sometime between April and June. Others, such as New York and California, essentially operate year-round. A few states, such as Texas, Arkansas, and Montana do not meet every year.
- Your state's *legislative website* is an excellent resource for state policy. Visit it frequently and explore it thoroughly for *legislator contact* information, biographies and session calendars.
- *Join the mailing list for your legislators.* This will allow you to find out about and attend local community events; especially town halls where you can speak publicly on Alzheimer's issues and raise awareness.
- *Visit state legislators while they are in their districts.* State legislators are generally more accessible than members of the U.S. Congress, and are even more so when session is out and they are at home in their districts. For part-time legislatures, mid-summer, fall, and early winter are ideal windows to schedule in-district visits. For full-time legislatures, you will have to be mindful of the recess schedules as they will come at intervals throughout the year, not unlike the U.S. Congress. Whether full or part-time, most state legislators come home over the weekends and often have community events during their time at home.
- Visit your local Alzheimer's Association chapter website at <http://alz.org/apps/findus.asp>

Alzheimer's Association 2015 Coordinated State Policy Priorities

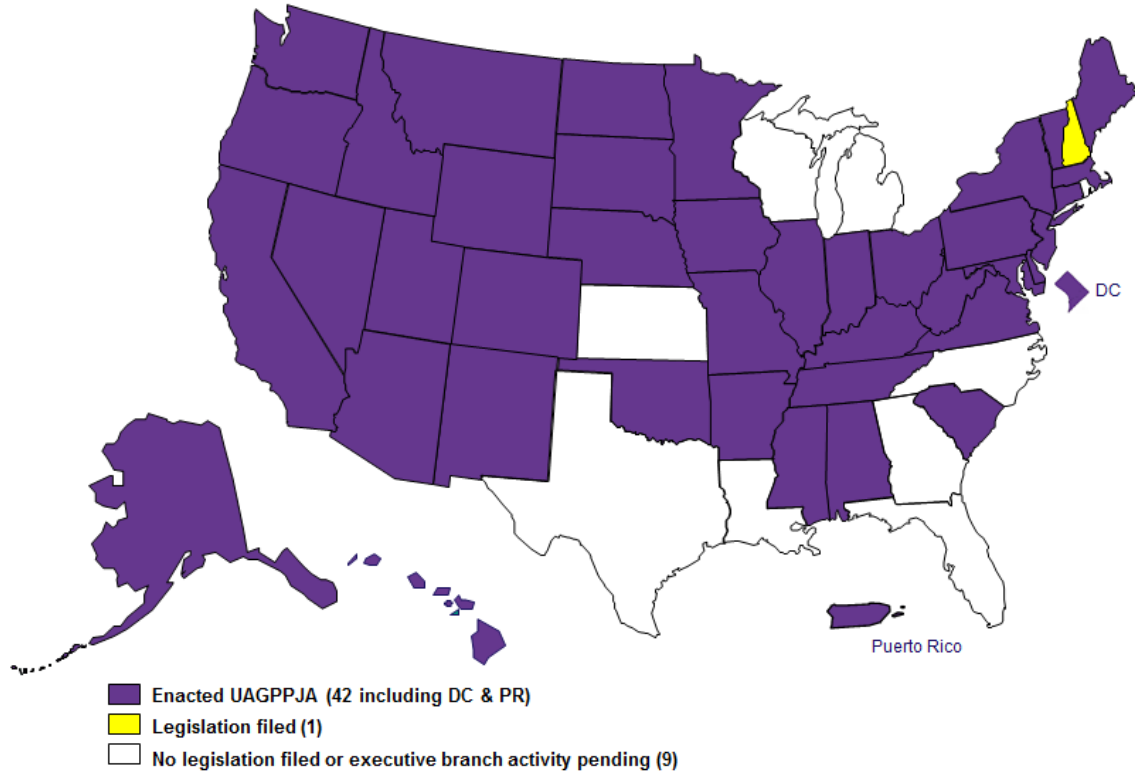
To achieve meaningful progress, every state must tackle Alzheimer's not only as an aging issue, but also as a public health crisis. Alzheimer's is a pivotal public health battle, and state governments stand on the front line. The Association calls on state policymakers to take bold action to confront this epidemic, focusing on these coordinated policy priorities:

- **Develop and implement a comprehensive state government Alzheimer's disease plan.**
 State Alzheimer's disease plans create the infrastructure and accountability necessary to confront the sweeping economic and social impact of this disease. By bringing together essential stakeholders – such as state agency officials, legislators, care providers, family caregivers, and people with Alzheimer's – the state planning process is able to identify critical issues, explore solutions, and construct a roadmap to guide a state's development into a dementia-capable state. Every state should develop a State Alzheimer's Disease Plan, and in those states that already have a published plan, efforts should be undertaken to ensure that the plan's recommendations are fully implemented.
- **Adopt uniform adult guardianship legislation.**
 States should ensure that their policies on advance directives and care planning reduce the complexity of end-of-life decision-making. One important step is to enact the budget-neutral Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (UAGPPJA), as approved by the Uniform Law Commission. UAGPPJA establishes a framework for courts in different states to communicate about adult guardianship cases and thus makes the resolution of multi-state jurisdictional issues easier for family members.
- **Improve dementia training.**
 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. Historically, mandatory training laws have required a minimum number of hours of training, but have not addressed the need for competency in dementia care. States should ensure that competency measures are integrated into dementia training requirements.
- **Increase state based surveillance through the Behavioral Risk Factor Surveillance System (BRFSS).**
 Obtaining a more definitive picture of Alzheimer's is essential to any successful strategy to combat the disease. Recent work by the Centers for Disease Control and Prevention now enables states to collect data on the impact of cognitive impairment and Alzheimer's disease using the existing state Behavioral Risk Factor Surveillance System (BRFSS). Two modules are available: a Cognitive Impairment Module and a Caregiver Module. States should include these two modules in their state BRFSS to provide a better understanding of – and to identify opportunities for reducing – the impact of this devastating disease.
- **Preserve Medicaid.**
 Among individuals with Alzheimer's, 75 percent will be admitted to a nursing home by the age of 80 (compared to only 4 percent of the overall population). As a result, Medicaid is critical for many people with Alzheimer's. While Medicaid spending constitutes one of the largest items in most state budgets - and most states continue to face severe fiscal constraints - state policymakers must ensure that critical benefits are preserved.

State Government Alzheimer's Disease Plans



Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act



SAMPLE FOLLOW-UP LETTER FROM YOUR MEETING(S) WITH MEMBERS OR STAFF

[insert month/date]2015

VIA EMAIL or FAX

The Honorable *[insert first and last name]*
U.S. House of Representatives/U.S. Senate
Washington, DC 20515 (House)/ 20510 (Senate)
Attention: *[member of Congress or staff]*

Dear Representative/Senator *[insert last name]*:

I am writing to thank *[you and/or members of your staff]* for meeting with *[list advocates in attendance]* on March 25, 2015 to discuss federal Alzheimer's initiatives. Over 5 million people currently have Alzheimer's disease - a number that could increase to as many as 16 million people by 2050 unless science finds a way to slow progression or delay onset.

We discussed *[your / the Rep.'s / Senator's]* stance on supporting the well-being and financial security of families by asking you to please:

1. Show your support for a strong National Alzheimer's Plan by sending a letter to the Chair and Ranking Member of the Appropriations Committee supporting an additional \$300 million for Alzheimer's research at the National Institutes of Health (NIH).
2. Cosponsor the HOPE for Alzheimer's Act, which will ensure Medicare beneficiaries newly-diagnosed with Alzheimer's disease and their families receive comprehensive care planning services and documentation of the diagnosis in the medical record. HOPE will also educate health care providers on the benefit and require that recommendations are made to eliminate any beneficiary access barriers.

A group of advocates from your district who were not able to join us in Washington are eager to meet with *[you or name of member]* in your *[insert name of closest city to chapter office in Rep.'s district/Senator's state]* office during the next Congressional recess to follow up on these issues.

Please contact *[insert name]* at *[insert telephone number and email address]* should you have any additional questions about the Alzheimer's Association or our federal priorities.

Sincerely,
[insert Name]
[insert Title]

Year-Round Advocacy

January

Welcome Back
Congress

HELLO
MY NAME IS

Advocate

February

Telephone
Outreach



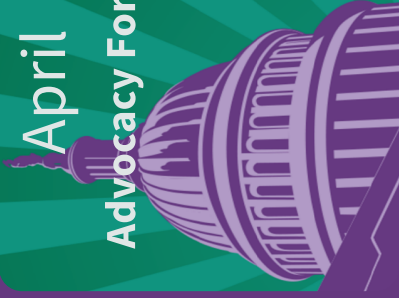
March

District Meetings



April

Advocacy Forum



May

District Meetings



June

ALZHEIMER'S
& BRAIN

awareness month

alzheimer's association®

July

Media Outreach



August

Town Halls & Coffee
with Congress



September

Walk
to End
Alzheimer's



October

Advocate
Recruitment
Month



November

Media Outreach:
Share Your Story



December

Learn about
Legislators
& Staff



Year-Round Advocacy

Continuous, year-round efforts advocating back home make all the difference. Your work shouldn't be something that only takes place in Washington D.C. **Partner with your local Alzheimer's Association chapter staff** to try some of the following ideas throughout the coming year. The activities and times are suggestions as many can occur at the same time or at various times of the year.

April/May: District-Forum-District (DFD) Meetings

Action Item: Attend a Meeting. Schedule or join the third DFD meeting in your local district as a follow-up to your meeting in D.C. *District - Forum - District* (DFD) is a program designed to maximize the impact of Forum visits on Capitol Hill. By meeting with members of Congress and/or their staff in local, congressional district offices before and after the Forum, you amplify the message that Alzheimer's disease must be a national priority as well as hold congressional leaders accountable.

May/June: Town Halls & Local Events

Action Item: Attend a local event. Legislators will be setting up town hall meetings and other in-person events during their "recess" (aka Constituent or State work week). Now is a great time to make plans to attend. Remember to engage the policymaker before, during and after the event via their social media profile(s) and in-person at the event.

June: Alzheimer's and Brain Awareness Month (ABAM)

Action Item: Go purple. Ask your federal, state and local elected officials to publicly express their support for Alzheimer's initiatives throughout the month. Work with your chapter staff to **draft a declaration, proclamation or public statement** for those officials. Ask them to wear purple and to post Alzheimer's related messages to their websites and social networks. And don't forget to invite them to participate in events like **The Longest Day** on June 21. www.alz.org/thelongestday

July: Media Messaging & Local Events

Action Item: Write about Alzheimer's. Write a letter to the editor, editorial, or blog entry for a local publication. Your chapter can provide you with fill-in-the-blank templates. Share your story. Urge readers to contact their representatives and ask for their support on policy/legislation. Bring awareness of policy issues to local events (parades, fairs, etc) including July 4th holiday and weekend events.

August/September: Town Halls, Coffees with Congress and Candidate Events

Action Item: Be a vocal participant in a local event. This is the height of the campaign season, so many candidates and elected officials host town halls and other community events. The Alzheimer's Association will also be hosting its own event series. Attend an event and talk about Alzheimer's. Be sure to wear purple and invite your friends.

September/October: Walk to End Alzheimer's® and Recruitment

Action Item: Recruit others to join our movement. Get involved with your local Walk to End Alzheimer's. Assist local organizers with petition drives and recruitment efforts. Invite elected officials to participate in-person or to submit a written declaration.

November: National Caregiver Month

Action Item: Share the stories of caregivers and their loved ones with local media (radio, television, newspapers, blogs). Work with your chapter to connect their stories with the Association's legislative "ask" and emphasize the many ways elected officials can improve the lives of their constituent caregivers.

December/January: Legislator Research

Action Item: Learn more about your legislators and their staff. In many cases, knowing staff can move your issue forward even faster than knowing the policymaker. Many D.C. policy staff make their way to the district or state during November and December. Get to know them; they have a direct line to the Member. Ask how they like to communicate - do they prefer email, phone or personal visits?

February/March: Prepare for Advocacy Forum

Action Item: Prepare for the DFD Program and the next Alzheimer's Advocacy Forum. It's that time of year again – the Alzheimer's Advocacy Forum. As you prepare to meet with legislators in D.C., practice delivering a message that will resonate using the tips in this guide. Hold the first of your three District-Forum-District (DFD) meetings with your Representative in the district office and tell them you'll be attending the Forum.

Year-round Activities:

Recruit, recruit, recruit. Urge friends, family and others in your community to get involved. Urge them to sign up at www.alz.org/advocate.

Make phone calls. A phone call may be the most effective alternative to in-person meetings with elected officials. It never hurts to call a local office with new information or to urge action on a bill. Reaffirm your commitment to serve as a resource and point of contact on Alzheimer's issues.

Media Messaging. Radio? TV? Blogs? Newspapers? Social networks? Each can help you get the word out. Whether its sound bites, pictures, stories or helpful facts, find your "hook", learn a reporters' needs and you'll be on your way to free publicity. Share information with legislators on Twitter and Facebook, or find mutual connections on Linked-In. Monitor legislator activities for insights into their interests and actions, then communicate with them directly.

Take Action. Take action online via alerts sent by the Alzheimer's Association.

Report. Report your activities at www.alzadvocacy.com

What to Do After Forum

While each individual will have a unique experience interacting with elected officials and their staff, we hope your experience at the 2015 Advocacy Forum is a productive and enjoyable one. Your efforts on behalf of yourself, the Alzheimer's Association and all of those affected by this disease are greatly appreciated. But don't let them go to waste. **Don't let Forum be the end!**

Sharing your story and asking your legislators to support our cause during the Forum is only one part of our continuous effort to affect public policy. In order to conquer Alzheimer's disease we need a sustained effort throughout the year, especially in your local Congressional district. Please reference the checklist provided below for simple tasks you can perform immediately following the Forum to capitalize on your time in Washington D.C. Then take a look at the Year-Round Advocacy Calendar(s) for other suggested activities throughout the year.

Post-Forum Checklist:

- Report your meeting(s) in AART (alzadvocacy.com).
- Send a "Thank You" letter to your elected officials (sample provided in this guide) via email or Tweet at your member of Congress on Twitter.
- De-brief with your local Alzheimer's Association chapter staff, Ambassador, team members and advocates from your area to share your experience.
- Work with your local Alzheimer's Association chapter staff to schedule follow-up meetings with your elected officials and complete the District-Forum-District (DFD) program.
- Download the ALZ Advocacy app for Android, iOS and Windows Phone at alz.org/advocateapp.
- Tell friends, family and social networks about your experience and invite them to learn more about the Forum at alz.org/forum.
- Share your experience with local media outlets via a Letter to the Editor.
- Add info@alz.org to your email program's "white list," "safe sender's" list or your personal contacts to ensure you receive important messages from the Alzheimer's Association.

MAKE ALZHEIMER'S A PRIORITY ON CAPITOL HILL

Each day, the Alzheimer's crisis grows worse for the more than five million Americans living with Alzheimer's, their loved ones, and the country as a whole. Help AIM support congressional champions fighting to make Alzheimer's a national priority. We have momentum. ***It's time to act!***

The Alzheimer's Impact Movement is a nonpartisan, nonprofit advocacy organization working in strategic partnership with the Alzheimer's Association to end Alzheimer's disease. Working together, the Association and AIM have made Alzheimer's a leading issue on Capitol Hill.

We are making progress. We have pushed Congress to increase funding for Alzheimer's research by almost 50% while overall medical research funding has remained flat, and to pass two of the Association's top legislative priorities – the National Alzheimer's Project Act and the Alzheimer's Accountability Act – setting the stage for continued progress.

But Washington still isn't acting fast enough. Alzheimer's is a leading cause of death in the United States yet it's the only one of the top 10 without a way to prevent, cure or even slow its progression. More than five million Americans are living with Alzheimer's today. And it's not just those with Alzheimer's who suffer – it's also their 15 million caregivers. Already the most expensive condition in America, these costs are set to skyrocket in the coming years.

AIM needs your help to continue to push Congress to end Alzheimer's.

AIM'S MOST IMPORTANT TOOL IS ITS POLITICAL ACTION COMMITTEE, AIMPAC.

AIMPAC supports members of the United States Congress from both political parties with a priority on those who are proven Alzheimer's champions and who have the most influence over the outcome of our legislative priorities.

Only members of AIM can contribute to AIMPAC. Individuals can join and maintain their AIM membership with a contribution of at least \$20 per year.



For more information about the Alzheimer's Impact Movement email:

info@alzimpact.org

 @ALZIMPACT

 FACEBOOK.COM/ALZIMPACT

CREATE A WORLD WITHOUT ALZHEIMER'S. SUPPORT AIM.

- AIM works to advance the legislative priorities of its sister organization, the Alzheimer's Association.
- AIM complements the advocacy efforts of the Alzheimer's Association. AIM ensures that our movement can engage Congress with our agenda throughout their lives as members – both in the congressional office and on the campaign trail.
- AIM is strictly bipartisan. Our supporters come from across the political spectrum, united by the conviction that Alzheimer's must be confronted now. Our supporters are both determined and pragmatic. They know that for our cause to succeed on Capitol Hill, we need champions from both parties.
- AIM members have access to information and opportunities available nowhere else. This is one way that AIM conveys its appreciation to some of the most remarkable supporters of the Alzheimer's movement – men and women who support AIM as part of their commitment to do all they can to end Alzheimer's.
- **Your support** for AIM ensures we can bring the Alzheimer's agenda before Congress whether these members be on the Hill or on the campaign trail. **Become an AIM member.** Join us as we press the fight to end this devastating disease.

JOIN THE MOVEMENT TO END ALZHEIMER'S AT ALZIMPACT.ORG





2015 Congressional Calendar

- Senate in session
- House in session
- Both chambers in session
- Both chambers in recess
- Federal holiday

January

M	T	W	T	F
			1 New Year's Day	2
5	6 Senate & House convene	7	8	9
12	13	14	15	16
19 MLK Jr. Day	20	21	22	23
26	27	28	29	30

February

M	T	W	T	F
2	3	4	5	6
9	10	11	12	13
16 Presidents Day	17	18	19	20
23	24	25	26	27

March

M	T	W	T	F
2	3	4	5	6
9	10	11	12	13
16	17	18	19	20
23	24	25	26	27
30	31			

April

M	T	W	T	F
		1	2	3 Good Friday & Passover Begins
6	7	8	9	10 Passover Ends (4/11)
13	14	15	16	17
20	21	22	23	24
27	28	29	30	

May

M	T	W	T	F
				1
4	5	6	7	8
11	12	13	14	15
18	19	20	21	22
25 Memorial Day	26	27	28	29

June

M	T	W	T	F
1	2	3	4	5
8	9	10	11	12
15	16	17	18	19
22	23	24	25	26
29	30			

July

M	T	W	T	F
		1	2	3 Independence Day (Federal holiday)
6	7	8	9	10
13	14	15	16	17
20	21	22	23	24
27	28	29	30	31

August

M	T	W	T	F
3	4	5	6	7
10	11	12	13	14
17	18	19	20	21
24	25	26	27	28
31				

September

M	T	W	T	F
	1	2	3	4
7 Labor Day	8	9	10	11
14	15 Rosh Hashanah ends (begins 9/13)	16	17	18
21	22 Yom Kippur begins	23 Yom Kippur Ends	24	25
28	29	30		

October

M	T	W	T	F
			1	2
5	6	7	8	9
12 Columbus Day	13	14	15	16
19	20	21	22	23
26	27	28	29	30

November

M	T	W	T	F
2	3	4	5	6
9	10	11 Veterans Day	12	13
16	17	18	19	20
23	24	25	26 Thanksgiving	27
30				

December

M	T	W	T	F
	1	2	3	4
7 Hanukkah begins (12/6)	8	9	10	11
14 Hanukkah ends	15	16	17	18
21	22	23	24	25 Christmas Day
28	29	30	31	

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Web www.alz.org
202 393 7737 (p)
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alzheimer's  association®

THE BRAINS BEHIND SAVING YOURS.™