



2018 ALZHEIMER'S ASSOCIATION  
AIM ADVOCACY FORUM PROGRAM

June 17-19

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

#alzforum



# WELCOME



Dear Alzheimer's Advocate,

Welcome to the 2018 Alzheimer's Association AIM Advocacy Forum! We thank you for joining us in Washington for the nation's premier Alzheimer's advocacy event. Whether this is your first year or you've participated before, we know the days ahead will be empowering and inspirational.

This year marks our 30th Advocacy Forum, and as we reflect back, we have a lot to be proud of and to celebrate. Working together we have compelled policymakers in all branches of government across the country to act. We've achieved the passage of landmark legislation including the the National Alzheimer's Project Act (NAPA), the Alzheimer's Accountability Act and the RAISE Family Caregivers Act. Alzheimer's and dementia research funding at the National Institutes of Health (NIH) has quadrupled since the passage of NAPA as a result of our advocacy. Nearly every state has developed and is implementing

a state Alzheimer's plan. And, thanks to your work on the HOPE for Alzheimer's Act, today people with cognitive impairments have access to critical care planning services through Medicare.

These achievements are due to the power of your advocacy not just here in Washington during the Advocacy Forum, but to the work you do 365 days a year.

**But we're not done.  
More work remains.**

Over the next three days, as you meet with fellow advocates for networking, training and education, you'll experience what it truly means to be part of the Alzheimer's community, as we advance policies to improve the lives of everyone affected by dementia.

In the following pages, you'll find everything you need to make the most of your Advocacy Forum experience, including detailed information about our federal and state priorities, and tips and resources on how to successfully advocate for the Alzheimer's community in Washington and at home. You'll also learn more about the role of the Alzheimer's Impact Movement (AIM) and how you can elevate AIM's power throughout the year.

We hope you'll share your Advocacy Forum experience with people unable to come to Washington. Be sure to follow our social media accounts and use #alzforum and #ENDALZ to continue the conversation online.

This disease is one of the most critical public health issues in America. That's why we are unrelenting advocates for public policy that advances research and improves access to care and support services. Thank you for joining us in the fight.

Sincerely,  
The Alzheimer's Association  
AIM Public Policy Team

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# 2018 ALZHEIMER'S DISEASE FACTS AND FIGURES

ALZHEIMER'S DISEASE IS THE

6<sup>TH</sup>

leading cause of death  
in the United States

**16.1 MILLION AMERICANS**

provide unpaid care for people with  
Alzheimer's or other dementias

These caregivers provided an estimated

**18.4 BILLION HOURS**

of care valued at over

**\$232 BILLION**

Between 2000 and  
2015 deaths from heart  
disease have decreased

11% 

while deaths from Alzheimer's  
disease have increased

 123%



**1 IN 3**

seniors dies  
with Alzheimer's  
or another  
dementia

It kills more than  
breast cancer and  
prostate cancer  
**COMBINED**



EARLY AND ACCURATE DIAGNOSIS  
COULD SAVE UP TO

**\$7.9** TRILLION

in medical and care costs

IN 2018, Alzheimer's and other  
dementias will cost the nation

**\$277 BILLION**

BY 2050, these costs  
could rise as high as

**\$1.1 TRILLION**



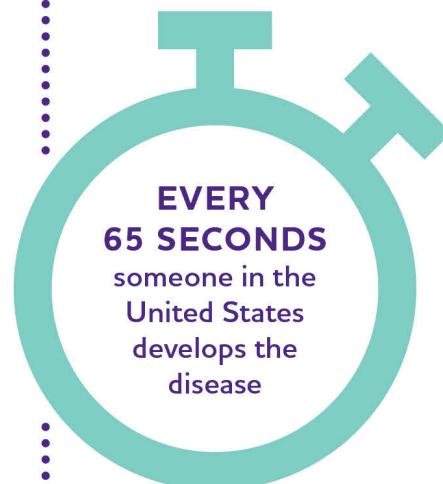
**5.7**  
MILLION

Americans are living  
with Alzheimer's

BY 2050, this  
number is projected  
to rise to nearly

**14**  
MILLION

**EVERY  
65 SECONDS**  
someone in the  
United States  
develops the  
disease



alzheimer's  association®

THE BRAINS BEHIND SAVING YOURS.®

# FACTSHEET

MARCH 2018

[alzimpact.org](http://alzimpact.org)

## 2018 Alzheimer's Disease Facts and Figures

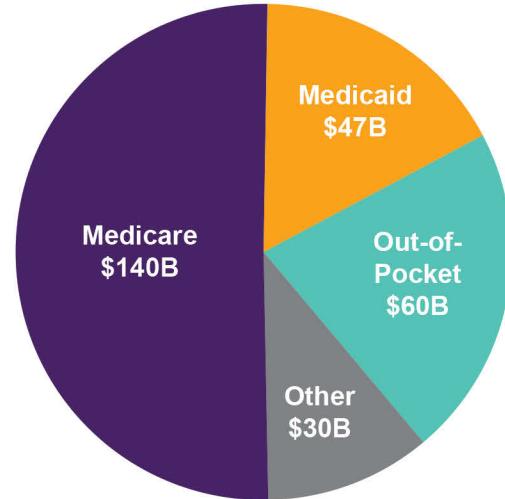
**Alzheimer's places a huge burden on the health care system, with annual costs exceeding a quarter of a trillion dollars.**

- In 2018, the direct costs to American society of caring for those with Alzheimer's will total an estimated \$277 billion.
- Unless something is done, in 2050, Alzheimer's will cost \$1.1 trillion (in 2017 dollars).

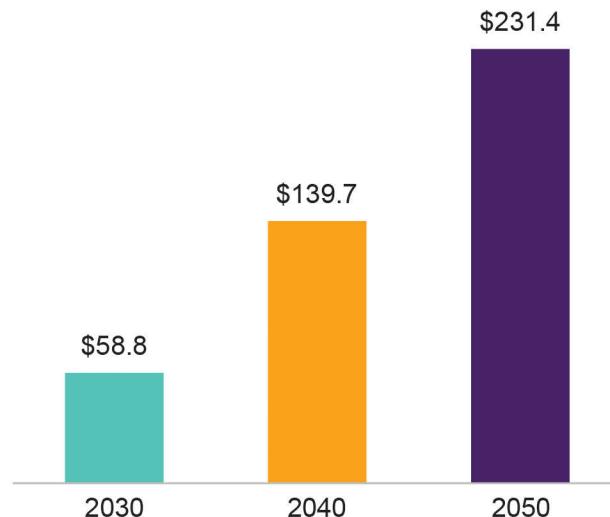
**One way to reduce costs is through earlier diagnosis.**

- Currently, as many as half of those with Alzheimer's disease are not diagnosed. And, for many of those who are diagnosed, the diagnosis does not occur until the late stages of dementia. Both drive up costs, which could be reduced with earlier diagnosis.
- Among all Americans alive today, if those who will get Alzheimer's disease were diagnosed when they had mild cognitive impairment (MCI)—before dementia—it would collectively save \$7 trillion to \$7.9 trillion in health and long-term care costs.
- In the year 2050 alone, costs would be \$231.4 billion lower than they would otherwise be.
- On an individual level, cumulative health and long-term care spending from one year prior to diagnosis until death would be, on average, \$64,000 lower if diagnosis occurred in the MCI stage.

**2018 Costs of Alzheimer's = \$277 Billion**



**Annual Savings with Early Diagnosis of Those Alive Today**  
(in billions of 2017 dollars)



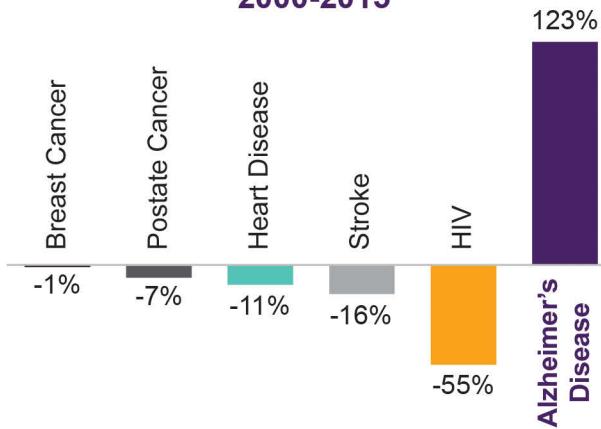
## Alzheimer's not only costs—it kills. And deaths have more than doubled since 2000.

- Alzheimer's disease is the sixth leading cause of death in the United States and the fifth leading cause of death for those aged 65 and older.
- Deaths from Alzheimer's increased 123 percent from 2000 to 2015, while deaths from other major diseases (including heart disease, stroke, breast and prostate cancer, and HIV/AIDS) decreased.
- Alzheimer's is the only cause of death among the top 10 in America that cannot be prevented, cured, or even slowed.

## Alzheimer's disease places a huge burden on America's families.

- Nearly half of all caregivers who provide help to older adults do so for someone with Alzheimer's or another dementia.
- In 2017, 16 million family members and friends provided 18.4 billion hours of unpaid care to people with Alzheimer's and other dementias, at an economic value of more than \$232 billion.
- Of the total lifetime cost of caring for someone with dementia, 70 percent is borne by families—either through out-of-pocket health and long-term care expenses or from the value of unpaid care.
- The annual out-of-pocket spending incurred by dementia caregivers—including on household and personal care expenses—is nearly twice as high as that incurred by caregivers of people with other conditions.
- The physical and emotional impact of caregiving on Alzheimer's and other dementia caregivers resulted in an estimated \$11.4 billion in increased caregiver health costs in 2017.

## Change in Number of Deaths 2000-2015



## The burden on families and the health care system is only going to increase as the number of Americans living with Alzheimer's rapidly grows.

- Today, 5.7 million Americans are living with Alzheimer's, including an estimated 200,000 under the age of 65.
- Nearly two-thirds of those with Alzheimer's—3.4 million—are women.
- Every 65 seconds, someone in America develops Alzheimer's—resulting in nearly a half million new cases this year.
- By 2050, someone in the United States will develop Alzheimer's every 33 seconds. At that time, the total number living with Alzheimer's is projected to reach 13.8 million.

## Facts in Your State

The 2018 *Alzheimer's Disease Facts and Figures* report also contains state-by-state data on the impact of the disease. Find the full report and information on your state at [alz.org/facts](http://alz.org/facts).

# PUBLIC POLICY VICTORIES

*The Alzheimer's Association, the Alzheimer's Impact Movement (AIM), and our dedicated network of advocates are leading the fight to end Alzheimer's!*

**Created the concept and drafted the language of the Alzheimer's Accountability Act (AAA).** The Alzheimer's Association and AIM were the only organizations leading the effort to gain support for the bill in Congress. Today, the National Institutes of Health releases its requested research budget for Alzheimer's — one of only three diseases to be singled out.

**Worked with state governments** to create State Alzheimer's Plans in nearly every state.

**Conceived of and championed the HOPE for Alzheimer's Act** to provide Medicare coverage for comprehensive care planning services for those living with Alzheimer's disease and other cognitive impairments. Because of our efforts, cosponsorship soared to include two-thirds of Congress. We also led extensive meetings with the Centers for Medicare & Medicaid Services (CMS) on the critical need for this benefit. As a result, beginning in January 2017, Medicare began paying for cognitive and functional assessments and care planning.

**Developed with Congress the National Alzheimer's Project Act (NAPA),** resulting in the first National Plan to Address Alzheimer's Disease with the goal of preventing and effectively treating Alzheimer's by 2025.

**Propelled the U.S. government to rise to the Alzheimer's challenge,** resulting in quadrupling Alzheimer's and dementia research funding since the passage of NAPA, including a historic \$414 million increase for FY2018.

**Made Alzheimer's a national priority** on the 2016 campaign trail. Alzheimer's became an issue during debates, in candidate advertising, and for the first time, an incoming president declared Alzheimer's would be a priority.

**Supported and advocated for the RAISE Family Caregivers Act,** which requires the Department of Health and Human Services (HHS) to develop, maintain and periodically update a National Family Caregiving Strategy.

**Advanced the passage of Kevin and Avonte's Law,** legislation to protect seniors with Alzheimer's and dementia and children with developmental disabilities who are prone to wandering.

# MAKE YOUR STORY COUNT



Human beings (and yes, that includes Congress) are hard wired to learn through stories. Statistics simply aren't enough to challenge preconceptions of this disease; it takes authentic stories from constituents like you. That's the whole reason you're an Alzheimer's advocate! Don't try to weave a universal story out of statistics; they're genuinely interested in YOUR story. Tell it well. Put them in the moment. Inspire them to retell it. Make it their story too. Then connect it to your ask. Here's how.

## Tell the Story of SELF

### Why are you an advocate?

- » **Paint a picture of life before Alzheimer's.**  
Why should they identify with you?
- » **Put them in the moment of diagnosis/realization.**  
First person. Present tense. Sensory details. It's OK to get emotional!
- » **Share moments of struggle.**  
Do they relate to our ask? What inspired you to become an advocate? What have you learned?

## Find the Story of US

### Why is your cause theirs too?

- » **"Do you know somebody with Alzheimer's?"** Give space to tell their story or say how lucky they are.
- » **Find common ground.** Do a bit of research to explore how your story might relate to their background and policy interests.
- » **All politics is local!** Share local stats, events and impacts on constituents.
- » **Say Thank You!** There's always something. Say how it matters to YOU.

## Tell the Story of NOW

### Why is inaction no longer an option?

- » **Deliver the ask.**  
Let the legislative collateral guide you.
- » **Don't bluff!**  
"I don't know, but we will get back to you" is a great excuse for our Federal Affairs team to follow-up.
- » **Finish on the personal.**  
Tie back to the story of self. Share a photo of a loved one.

**Stuck?** Try framing your story with some of these prompts:

1. Once upon a time...
2. And every day...
3. Until one day...
4. And because of this... (repeat as needed)
5. Until finally...
6. And ever since that day...

# TAKE THE NEXT STEP IN ALZHEIMER'S ADVOCACY

Could you be an Alzheimer's State Champion? Know somebody with skills and interests to round out your Alzheimer's Congressional Team? Visit [alzimpact.org/volunteer](http://alzimpact.org/volunteer) to learn more and apply online.



## Join Our Advocacy Team

With help from advocates like you, we've passed critical legislation and quadrupled federal research funding since 2011. But our work isn't done and we need dedicated advocates like you to build on this success in Congress and in every state capital.

We'll train you to advocate in a variety of ways, some of which take just an hour or two every few months. Whatever your experience and availability, we're eager to have you on our advocacy team!

### Will you join us?

#### Alzheimer's State Champions

cultivate multifaceted, year-round relationships with targeted state officials.

#### Alzheimer's Ambassadors

develop deep, one-to-one relationships with their assigned members of Congress.

#### Alzheimer's Congressional Team members

bring their own unique stories, relationships and skills to complement the work of an Ambassador.

#### Alzheimer's Advocacy Volunteer Application

Please select the advocacy activities that interest you. Depending on your interests, skills and location, we'll reach out to discuss an Alzheimer's State Champion, ACT member and/or Ambassador role that makes sense for you.

##### **Meet with elected officials**

Lend your voice in district offices, state capitols and at the Advocacy Forum in D.C.

##### **Raise awareness through local media**

Partner with chapter staff to draft letters-to-the-editor and pitch stories.

##### **Spark social media conversations**

Engage online, inspire novices, recruit new advocates and monitor legislator accounts to comment/tweet.

##### **Coordinate events and volunteers**

Recruit and mobilize volunteers, organize events and work with event committees.

##### **Support the Alzheimer's Impact Movement (AIM)**

Promote AIM membership. Engage with campaign staff, donors and events.

##### **Call on your connections**

Use your relationships with legislators and partner organizations to make calls at key moments.

##### **Share your unique perspective as a...**

(person with dementia, researcher, young person, etc).

**Apply online today:**

[alzimpact.org/volunteer](http://alzimpact.org/volunteer)

# TIPSHEET: SPARK SOCIAL MEDIA CONVERSATIONS

*Social networks have revolutionized advocacy in ways we couldn't have even imagined just a few years ago. With a social media connected phone in nearly every American's pocket, it's easier now more than ever for you to instantly and effectively engage with your elected officials.*

*Unlike other advocacy tools — which often feel like sending messages into a void to be reviewed, maybe, by staff — social media often enables direct interaction with your legislators. Today, the vast majority of legislators run (or at least monitor) their own social media accounts and are eager to gather feedback from their constituents.*

*Whether you've been on social media for years or haven't yet created an account, you can make a big difference in the fight to end Alzheimer's, with just a handful of posts.*



## Mentioning & Tagging

Mentioning or Tagging is an effective and easy way to engage legislators online. On Twitter and Instagram, simply mention their handle (i.e. @SenatorName) in your post. On Facebook, tag them by typing "@" followed by their name and they will receive a notification.



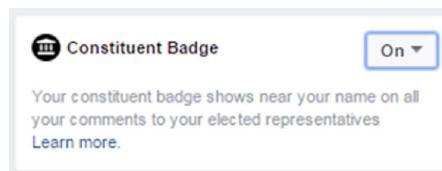
## Retweeting & Commenting

Legislators use social media to reach their constituents. Reply and comment on their posts to make your voice heard and raise the issue of Alzheimer's. You can also retweet or share their posts, adding your thoughts. You can also share posts from AIM, your chapter or fellow advocates and tag your legislator to bring them into the conversation.



## #Hashtags

Hashtags link together a conversation and help you find posts to comment, share and engage in. Don't forget to include **#ENDALZ** in your posts. And other hashtags like **#alzforum** and **#Ask4Alz** can also be used. But, best practice is no more than four clickable items per post.



## Identify yourself as a constituent

Legislators want to hear from their own constituents but it can be difficult to verify constituents on social media. Visit [fb.com/townhall](http://fb.com/townhall) to turn-on Facebook's "constituent badge." On other platforms, mention your town/neighborhood in your profile and include photos from recognizable local events or landmarks.



## Find political events on Facebook

Facebook's events feature is a great way to find opportunities to connect with your elected officials and other advocates in your community. After following your elected officials, visit [fb.com/events](http://fb.com/events) and check out the "popular with friends" category. Select "interested" for any local political events you see and Facebook will notify you of similar events in the future. Make sure to go early and stay late to network and discuss the Alzheimer's crisis. And don't forget to wear your purple!



## Expand Your Network with LinkedIn

Elected officials aren't your only audience. In many cases you can

# TIPSHEET: SPARK SOCIAL MEDIA CONVERSATIONS

establish direct connections with legislative staff, local influencers, other advocates and community allies via your professional network. LinkedIn is the most prominent professional social network. You can share AIM posts, your own letters-to-the-editor and relevant Alzheimer's information. [linkedin.com/company/alzheimer's-impact-movement/](https://www.linkedin.com/company/alzheimer-s-impact-movement/)



## Take the Picture. Share it.

Posting an image or video can increase the likelihood of your audience engaging with your content. Whenever possible include a photo and tag the individuals, organization and location. If your photo includes an elected official or their staff, be sure to get their permission before posting. If you have more than one great photo, try posting them together as an album.



## Broadcast yourself.

If you have unique content to share with your audience consider a "live" stream on Facebook, Twitter, or Instagram. Make sure you have a steady device and you promote it in advance so your followers know to tune in. Save clips so you can share highlights later for those who may have missed it.

## The Anatomy of a Tweet



## Worksheet: Get Connected

Do some homework by finding your legislator and your team members on leading social media platforms. "Follow" or "friend" them on each platform to engage them, learn about upcoming events, and to make tagging them easier in future posts and photos.



Facebook



Twitter



Instagram

**Legislator's official account:** \_\_\_\_\_

**Legislator's campaign account:** \_\_\_\_\_

**Any key staff account(s)?:** \_\_\_\_\_

**Alzheimer's Impact Movement:** [fb.com/alzimpact](http://fb.com/alzimpact) [@alzimpact](https://twitter.com/alzimpact) [@alzimpact](https://www.instagram.com/alzimpact)

**Alzheimer's Association:** [fb.com/actionalz](http://fb.com/actionalz) [@alzassociation](https://twitter.com/alzassociation) [@alzassociation](https://www.instagram.com/alzassociation)

**Your Chapter:** \_\_\_\_\_

**Your Chapter Policy Staff:** \_\_\_\_\_

**Yourself!** \_\_\_\_\_

**Your team/Fellow Advocates:** \_\_\_\_\_

Would you believe 10% of Congress is active on Snapchat?

Note other platforms that your legislator uses:

**Google Plus:** \_\_\_\_\_ **Snapchat:** \_\_\_\_\_

**LinkedIn:** \_\_\_\_\_ **You Tube:** \_\_\_\_\_

**Pinterest:** \_\_\_\_\_

# LEGISLATIVE MEETING TIPS



## SHOW YOUR COLORS

Wear something purple (tie, scarf, sash, pin, etc.) to indicate that you are an Alzheimer's Association or Alzheimer's Impact Movement advocate.

## 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 elected official or staff member express his or her point of view.

## BE COURTEOUS

Even those who vehemently disagree with your message 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.

## KEEP IT SIMPLE

Don't be too technical, too detailed, too complex or too oblique. Be direct, 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 chosen a spokesperson and stick with that decision.

## NEVER TELL A LIE

Your reputation is everything. You lose credibility if you lie. If you don't know the answer to a question, tell them you don't know, but offer to 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.

## EXCHANGE INFORMATION

When meeting with staff be sure to exchange contact information or business cards.

## SAY THANK YOU

Remember to call or send a note to your elected official to remind them of your visit, and thank them for their time and support.

## SHARE YOUR EXPERIENCE

Upload and post pictures of your meeting to your social networks and blogs. Remember to tag and share with your elected officials.

## REPORT YOUR ACTIVITY

Please make sure to enter your meeting report on the Alzheimer's Impact Movement (AIM) website.

[alzimpact.org](http://alzimpact.org)

# LEGISLATIVE MEETING CHECKLIST

Below are some suggested ways to have a successful State Caucus. These Caucus meetings are an excellent opportunity to prepare for your Capitol Hill meetings. You'll gather with advocates from your state to practice telling your story and make the legislative asks.

## OFF SITE PRE-MEETING

### Assign Roles and Assignments

- » Who is responsible for bringing materials to the meeting?
- » Who is going to handle introductions? Ex. Who we are, why we're here?
- » Who will deliver the opening line and show the collateral piece on the state of Alzheimer's?
- » Who is going to tell their story and show how it relates to the first issue?
- » Who is going to make the first "ask"?
- » Who is going to tell their story and show how it relates to the second issue?
- » Who, if applicable, is going to make the additional ask(s)?
- » Who is going to conclude the meeting and ask for a photo?

### Logistics

- » Meet with other advocates from your state in the room listed in the the Blue Sheets provided in your Registration Bag.
- » Get your Capitol Hill meeting schedule from your chapter staff contact.
- » Have the meeting time and location been confirmed?
- » Do all attendees have the legislative office's contact information?

## ON SITE PRE-MEETING

- » Are all meeting attendees present and accounted for? If so, quickly reconfirm assigned roles before entering office.

## POST-MEETING

- » Who will post a photo from the meeting to Twitter and Facebook?
- » Who will submit the meeting report to [alzimpact.org](http://alzimpact.org)?
- » Who will follow-up with the legislative office? Ex. Provide answers to pending questions, additional materials.
- » Who will update/debrief participants and provide next steps?

# 2018 FEDERAL PRIORITIES

Alzheimer's 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 crisis now.

## 1 Increase the commitment to Alzheimer's research

Alzheimer's is the most expensive disease in America, costing an estimated \$277 billion in 2018. By mid-century, the number of people with the disease is set to nearly triple. And, the costs are projected to more than quadruple to \$1.1 trillion, with two-thirds of these costs paid by Medicare and Medicaid. If we meet the first goal of the National Alzheimer's Plan to have an effective treatment by 2025, Medicare spending on those with the disease would be reduced 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 National Institutes of Health (NIH), the commitment continues to fall far short of the need. In 2018, for every \$100 that the NIH spent on Alzheimer's research, Medicare and Medicaid spent \$9,700 caring for those with the disease. Congress must continue its commitment to the fight against Alzheimer's and other dementias by increasing funding for Alzheimer's research by at least an additional \$425 million in fiscal year 2019.

## 2 Build an Alzheimer's public health infrastructure

Alzheimer's is an urgent public health crisis affecting millions of families across our country. Investing in a nationwide Alzheimer's public health response will help create population-level change, achieve a higher quality of life for those living with the disease and their caregivers, and reduce associated costs. *The Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act* (S. 2076/H.R. 4256) would provide this crucial investment by establishing Alzheimer's centers of excellence across the country and funding state, local and tribal public health departments to increase early detection and diagnosis, reduce risk, prevent avoidable hospitalizations, reduce health disparities, support the needs of caregivers and support care planning for people living with the disease. These important public health actions allow individuals with Alzheimer's to live in their homes longer and delay costly institutionalized care. The bipartisan bill would also increase the collection, analysis and timely reporting of Alzheimer's data, which is critical to identifying opportunities for intervention, helping stakeholders track progress in the public health response, and enabling state and federal policymakers to make informed decisions when developing plans and policies.

## 3 Educate providers on palliative and hospice care

Nearly half of all people with Alzheimer's and other dementias are in hospice care at the time of their death. However, less than half of surveyed nursing homes have some sort of palliative care program. For people with advanced dementia, such team-based care — which focuses on managing and easing symptoms, reducing pain and stress, and increasing comfort — improves quality of life, controls costs, and enhances patient and family satisfaction. But, as the demand for such coordinated care grows with the aging population, more must be done to ensure an adequately trained workforce. *The Palliative Care and Hospice Education and Training Act* (S. 693/H.R. 1676) would increase palliative care and hospice training for health care professionals, launch a national campaign to inform patients and families about the benefits of palliative care, and enhance research on improving the delivery of palliative care.



# FACTSHEET

MARCH 2018

[alzimpact.org](http://alzimpact.org)

## Fiscal Year 2019 Alzheimer's Research Funding

### The escalating Alzheimer's epidemic has profound implications for government budgets.

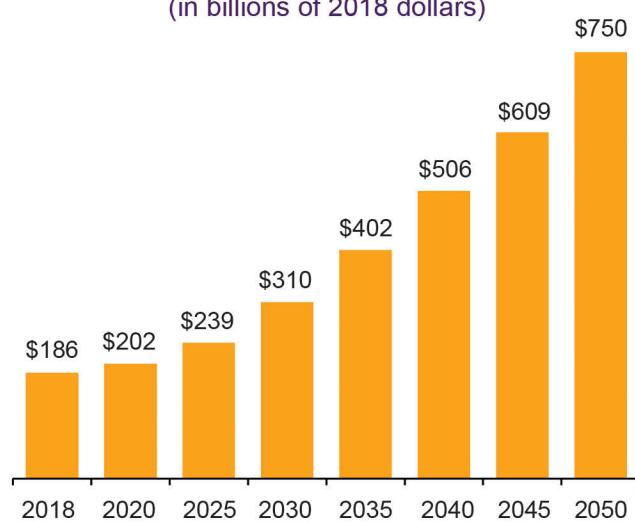
- Alzheimer's is the most expensive disease in America, costing more than heart disease and cancer.
- In 2018, caring for people with Alzheimer's and other dementias will cost the United States an estimated \$277 billion. Cumulatively between now and 2050, it will cost \$20.2 trillion—two-thirds of which will be borne by Medicare and Medicaid.
- One in every 5 dollars of Medicare spending is spent on people with Alzheimer's and other dementias.

### Despite the recent increased investment in Alzheimer's research, funding still falls short of the need.

- For fiscal year 2018, Congress provided an additional \$414 million in Alzheimer's research funding at the National Institutes of Health (NIH).
- With this increase, along with previous research investments, the NIH is expected to spend \$1.9 billion on Alzheimer's research in 2018.
- However, this still means that for every \$9,700 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 2018 dollars)



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

- The National Alzheimer's Plan has established a goal of developing preventions and effective treatments for Alzheimer's by 2025.
- Under the Alzheimer's Accountability Act, NIH scientists have released a Bypass Budget that outlines what is needed to reach that goal.
- Based on the targets outlined in the Bypass Budget, Congress should provide an additional \$425 million in Alzheimer's research funding in fiscal year 2019.

# RESEARCH FUNDING BACKGROUND

**ASK:** Please tell Senate/House leadership that you are supportive of an additional \$425 million in Fiscal Year 2019 (FY19) for Alzheimer's research activities at the National Institutes of Health (NIH).

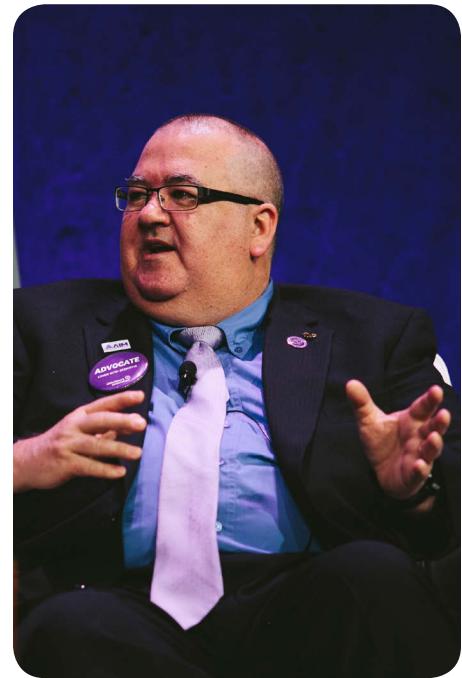
## Background

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 National Alzheimer's 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.

To achieve a core goal of the National Alzheimer's Plan of preventing and effectively treating Alzheimer's by 2025, Congress has bolstered support for Alzheimer's research at the NIH. In March 2018, Congress appropriated an historic \$414 million increase for Alzheimer's research funding in FY18, bringing the annual allocation to \$1.9 billion. This significant increase is an important investment in research that will provide relief for millions of Americans and to federal spending. However, the current funding level is still short of the total funding scientists believe is needed to meet the goal of finding a treatment or cure for Alzheimer's and other dementias by 2025.

## Making the Case for Research Funding

- » According to an NIA-funded study in the New England Journal of Medicine, Alzheimer's is the most expensive disease in America.
- » In 2018, the cost for caring for those with Alzheimer's was \$277 billion, with \$186 billion of that amount paid by Medicare and Medicaid. The annual costs are set to increase rapidly to \$1.1 trillion by 2050.
- » According to a 2015 report, a treatment that simply delayed onset of Alzheimer's by five years would lower Medicare spending on those with the disease by one-quarter in 2050 – and the federal government would recoup its research investment in less than three years.
- » The National Alzheimer's Plan has resulted in 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.
- » Congress must continue its commitment to the fight against Alzheimer's by increasing funding for Alzheimer's research by an additional \$425 million in FY19.



## Share Your Story

*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.*

# RESEARCH FUNDING TALKING POINTS

## Frequently Asked Questions

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.

### Q. Is this a programmatic request?

#### Suggested Response:

- » This is an individual letter of support for an increase in the overall level of funding for Alzheimer's research at the NIH. Letters of support can be sent up until the Labor-HHS Appropriations bill is passed.

### Q. NIH already receives funding for Alzheimer's; why the additional \$425 million?

#### Suggested Response:

- » Recent funding increases have been critical to progress toward the primary research goal of the National Plan to Address Alzheimer's Disease of effectively treating and preventing Alzheimer's by 2025.
- » The "Milestones" leave-behind highlights some of the important research advances made with these funding increases, including research into new biomarkers to detect the disease before the onset of symptoms and ways to build better animal

models to replicate the disease and enable preclinical testing of promising therapeutics.

- » The Alzheimer's Bypass Budget, released annually by the National Institutes of Health (NIH), specifies the resources scientists need to fulfill the primary research goal of the National Alzheimer's Plan. An additional \$425 million would allow the NIH to invest in collaborations that speed discovery, groundbreaking prevention trials, the testing of new therapeutics and many other opportunities.
- » Alzheimer's is the only one of the leading causes of death in the U.S. without a way to prevent, cure, or even slow its progression. 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.
- » 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 spending reduced by \$47 billion in 2030.

### Q. The FY2019 Bypass Budget requests an additional \$597 million for Alzheimer's research at NIH. Why are you advocating for a \$425 million increase?

#### Suggested Response:

- » NIH based its FY2019 request of a \$597 million increase on the assumption that Congress would enact the multi-million dollar **cut** in the President's FY2018 budget proposal, therefore starting with a lower baseline number.
- » The Alzheimer's Association and AIM based our FY2019 request of a \$425 million increase on the assumption that Congress would approve a multi-million dollar **increase** for FY2018, which Congress did in March 2018.
- » So while our requested increase is a lower dollar figure than the Bypass Budget, it represents a similar overall funding level for Alzheimer's research at NIH.

# RESEARCH FUNDING TALKING POINTS

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

**Suggested Response:**

- » The Alzheimer's Association and Alzheimer's Impact Movement agree that Congress should not pick the specific research projects to be funded — that is a job for scientists, not politicians.
- » Congress enacted the bipartisan Alzheimer's Accountability Act as part of the Fiscal Year 2015 omnibus appropriations bill (P.L. 113-235) to require the scientists at the NIH to submit a Bypass Budget, which is an annual Alzheimer's research budget proposal.
- » This ensures that Congress hears directly from scientists on what they will need to meet the nation's goal of finding a way of preventing or treating Alzheimer's by 2025, and equips Congress with the best information to determine necessary Alzheimer's research funding levels each year.

**Q. How would recent initiatives to address biomedical research funding, like the 21st Century Cures Act, impact funding for Alzheimer's research?**

**Suggested Response:**

- » The Alzheimer's Association strongly supported the 21st Century Cures Act. The legislation has the potential to accelerate Alzheimer's research projects at the NIH.
- » The 21st Century Cures Act directs nearly \$1.6 billion to the BRAIN Initiative over the next 10 years, which works to accelerate the development and implementation of innovative technologies. While this research may have an impact on Alzheimer's, it is not a substitute for the basic biomedical and translational research conducted by the National Institute on Aging that is so critical to advancing what we all hope will one day be an end to Alzheimer's.

**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. Simply ask them to contact a member of the Alzheimer's Association's Federal Affairs Team at 202.393.7737. Also indicate the interaction at [alzimpact.org](http://alzimpact.org) so a member of the Federal Affairs team can follow-up with that office.

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[alzimpact.org](http://alzimpact.org)

## BOLD Infrastructure for Alzheimer's Act

### How is Alzheimer's a public health issue?

- While Alzheimer's has been viewed as an aging issue, it also has an effect on a community level.
- Specifically, Alzheimer's meets the three-point criteria for identifying a public health issue: (1) the burden is large; (2) the impact is major; and (3) there are ways to intervene.

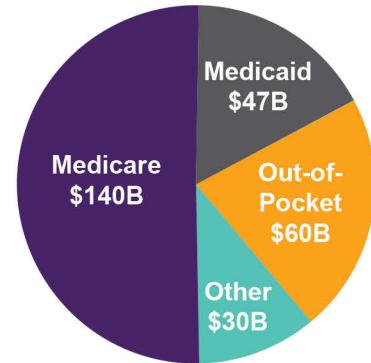
### How large is the burden?

- More than 5 million Americans have Alzheimer's.
- It is the most expensive disease in America; costs now exceed a quarter of a trillion dollars per year.
- And the burden is growing larger. The number of people living with Alzheimer's is projected to triple to as many as 16 million in 2050, and the costs are expected to rise to \$1.1 trillion.

### What Is Public Health?

Health care primarily involves medical treatment and care for particular individuals—that is, the prevention, treatment, and management of illness among individuals by medical professionals. Public health, on the other hand, works on a community level to protect and improve the health and safety of an entire community or group of people. Public health promotes healthy lifestyles, prevents illnesses and injuries, and detects and controls diseases. By working with diverse communities, public health expands the reach and impact of health care efforts.

### 2018 Costs of Alzheimer's = \$277 Billion



### How major is the impact?

- Due to the toll of caring for someone with Alzheimer's, caregivers have more than \$11 billion in additional health care costs each year.
- Among people with dementia, 1 in every 4 hospitalizations is preventable.
- Alzheimer's imposes a significant cost on federal and state budgets:
  - Two-thirds of the health and long-term care costs of caring for those with Alzheimer's are borne by Medicare and Medicaid.
  - One in every 5 dollars spent by Medicare is spent on people with Alzheimer's and other dementias.
- And the impact is growing larger. By 2050, 1 in every 3 Medicare dollars will be spent on someone with Alzheimer's and other dementias.

# BOLD INFRASTRUCTURE FOR ALZHEIMER'S ACT BACKGROUND

*ASK: Please cosponsor the bipartisan BOLD Infrastructure for Alzheimer's Act (S. 2076/H.R. 4256), which would create an Alzheimer's public health infrastructure across the country to implement effective Alzheimer's interventions and focus on public health issues such as increasing early detection and diagnosis, reducing risk and preventing avoidable hospitalizations.*

## Background

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) strongly support the bipartisan BOLD Infrastructure for Alzheimer's Act, which was introduced by Senators Susan Collins (R-ME), Catherine Cortez Masto (D-NV), Shelley Moore Capito (R-WV) and Tim Kaine (D-VA) in the Senate and Representatives Brett Guthrie (R-KY-2), Paul Tonko (D-NY-20), Chris Smith (R-NJ-4) and Maxine Waters (D-CA-43) in the U.S. House of Representatives.

## Making the Case for the BOLD Infrastructure for Alzheimer's Act

### Why the BOLD Infrastructure for Alzheimer's Act is needed:

- » About 50 percent of individuals living with Alzheimer's and other dementias have not been diagnosed.
- » Among individuals who are diagnosed with Alzheimer's, only 33 percent are aware of the diagnosis.
- » Early detection and diagnosis of Alzheimer's and other dementias allows people to access available treatments, build a care team, benefit from care planning

sessions, participate in support services, and enroll in clinical trials.

- » Early detection can also help physicians better manage a patient's comorbid conditions and avoid prescribing medications that may worsen cognition or function.
- » More than one quarter of all hospitalizations of people with dementia are preventable – at a cost to Medicare of nearly \$2.6 billion in 2013.
- » African-Americans are about two times more likely than white Americans to have Alzheimer's and other dementias.
- » Hispanics/Latinos are about one and one-half times more likely than whites to have Alzheimer's and other dementias.

As scientists continue to search for a way to prevent, cure, or slow the progression of Alzheimer's through medical research, public health can play an important role in promoting cognitive function and reducing the risk of cognitive decline. Investing in a nationwide Alzheimer's public health response will help create population-level improvements, achieve a higher quality of life for those living with the disease and their caregivers, and reduce associated costs.

The BOLD Infrastructure for Alzheimer's Act would accomplish these goals by directing the Centers for Disease Control and Prevention (CDC) to:

### Establish Alzheimer's Centers of Excellence:

- » The Centers will increase education of public health officials, health care professionals, and the public on Alzheimer's, brain health, and health disparities.
- » The Centers will also provide technical assistance to public health departments across the country in implementing effective Alzheimer's interventions.
- » These interventions will focus on priorities such as increasing early detection and diagnosis, reducing risk, preventing avoidable hospitalizations, reducing health disparities, supporting the needs of caregivers, and supporting care planning for people living with the disease.
- » Finally, the Centers will expand innovative public-private partnerships that focus on addressing cognitive impairment and health disparities.

# BOLD INFRASTRUCTURE FOR ALZHEIMER'S ACT TALKING POINTS

## **Award cooperative agreements to public health departments:**

- » This funding will help public health departments implement effective Alzheimer's interventions, including those identified by the Alzheimer's Centers of Excellence.
- » This funding will also help public health departments implement strategic actions identified in the Healthy Brain Initiative's Public Health Road Map.

## **Increase data collection, analysis and timely reporting:**

- » Cooperative agreements to public or nonprofit private entities will increase the analysis and timely public reporting of data on Alzheimer's, caregiving, and health disparities.
- » This data will be collected using tools like the Behavioral Risk Factor Surveillance System (BRFSS), the National Health and Nutrition Examination Survey (NHANES), and the National Health Interview Survey (NHIS).
- » This funding will also help monitor the progress of the Alzheimer's and caregiving objectives in the Healthy People 2020 report.

## **Frequently Asked Questions**

*During the course of your meetings with members of Congress and their staff, you may encounter some common questions regarding the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act. We have addressed some of these common questions below.*

### **Q. What is public health?**

#### **Suggested Response:**

- » Public health works on a community level to protect and improve the health and safety of an entire community or group of people.
- » Public health promotes healthy lifestyles, prevents illnesses and injuries, and detects and controls diseases.
- » By working with diverse communities, public health expands the reach and impact of health care efforts.

### **Q. Why is Alzheimer's a public health issue?**

#### **Suggested Response:**

- » Former Surgeon General and Director of the Centers for Disease Control and Prevention Dr. David Satcher has said, "Alzheimer's is the most under-recognized threat to public health in the 21st century."

- » Alzheimer's is a public health issue because it affects so many people around the country — over 5 million Americans — and has a major impact on our health care system and our government — with Medicare and Medicaid bearing two-thirds of the cost of caring for those with the disease.
- » There are known ways to intervene, such as promoting prevention and reducing risk, increasing early detection and diagnosis, and preventing avoidable hospitalizations.

### **Q. What role does CDC play in public health and Alzheimer's?**

#### **Suggested Response:**

- » As the nation's health protection agency, CDC protects people from public health threats, and responds when such threats arise.
- » The CDC's Healthy Brain Initiative, launched by Congress in FY2005, educates the public health community and health professionals about Alzheimer's, cognitive decline, and brain health.

# BOLD INFRASTRUCTURE FOR ALZHEIMER'S ACT TALKING POINTS

- » The Healthy Brain Initiative builds a strong evidence base for improving cognitive health and translates that foundation into effective public health practices in states and communities across the country.
- » The Healthy Brain Initiative also created the *Public Health Road Map* to support public health action in communities nationwide.

## **What is the Public Health Road Map?**

### **Suggested Response:**

- » The *Public Health Road Map* is a report that identifies strategic actions that state and local public health departments and their partners can take to promote cognitive functioning, address cognitive impairment, and help meet the needs of care partners.
- » The *Public Health Road Map* was developed as part of the CDC's Healthy Brain Initiative, through a partnership between the Alzheimer's Association and CDC.

## **What entities could be eligible for Centers of Excellence?**

### **Suggested Response:**

- » The BOLD Infrastructure for Alzheimer's Act allows CDC flexibility on what entities could be designated as Alzheimer's Centers of Excellence, so it is possible a Center could be

a university, health system, national organization, or public health institute.

## **How would the Alzheimer's Centers of Excellence interact with the public health departments?**

### **Suggested Response:**

- » The Alzheimer's Centers of Excellence would identify effective public health interventions and help public health departments implement those interventions at the state and local level.
- » The Centers of Excellence would also help public health departments implement the *Public Health Road Map* nationwide.

## **What is the difference between cooperative agreements and grants?**

### **Suggested Response:**

- » While grants and cooperative agreements both provide funding, cooperative agreements include substantial involvement from the federal government.
- » This substantial involvement allows the CDC more oversight of the funding it awards and provides additional accountability to ensure the funding recipient is accomplishing its objectives.

## **How much would the BOLD Infrastructure for Alzheimer's Act cost?**

### **Suggested Response:**

- » The bill has not been scored by the Congressional Budget Office (CBO), and there is no cost estimate for the bill. However, the Alzheimer's Association and AIM will continue to work with the bill's sponsors to determine the impact this bill would have on federal spending.

*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. Simply ask them to contact a member of the Alzheimer's Association's Federal Affairs Team at 202.393.7737. Also indicate the interaction at [alzimpact.org](http://alzimpact.org) so a member of the Federal Affairs team can follow-up with that office.*

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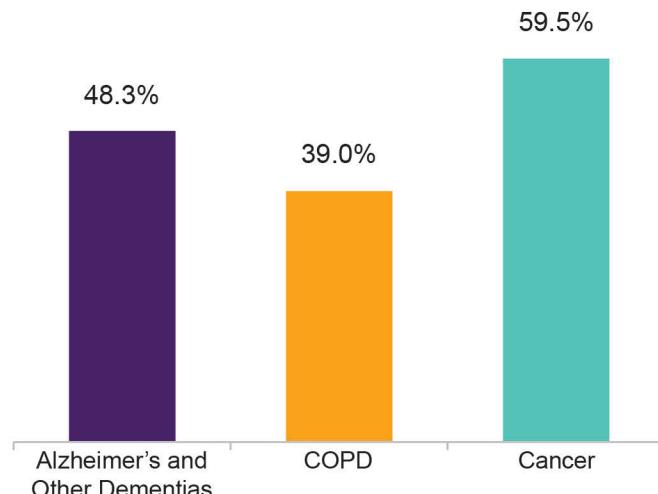
[alzimpact.org](http://alzimpact.org)

## PCHTA and Alzheimer's Disease

**Palliative and hospice care—with a focus on managing and easing symptoms, reducing pain and stress, and increasing comfort—can improve both the quality of care and quality of life for those with advanced dementia.**

- Observational studies have shown that as many as half of nursing home residents with advanced dementia have documented pain in the last weeks of life—and about a third have difficulty breathing or swallowing, or suffer from agitation.
- Individuals with advanced dementia who are enrolled in hospice have a lower rate of dying in the hospital, a lower rate of hospitalization in the last 30 days of life, and better symptom management.
- A recent study shows that nursing home residents with dementia who receive palliative care at the end of life, compared with those who do not receive such care, are:
  - more than 3 times less likely to have a hospitalization in the last 30 days of life
  - 3.2 times less likely to have an emergency room visit in the last 30 days of life.
- Families of individuals with dementia who are enrolled in hospice have a greater satisfaction with patient care.

### Percentage of Seniors Receiving Hospice Care at Time of Death, by Condition



**People with Alzheimer's and other dementias rely heavily on palliative and hospice care at the end of life.**

- Of all people living with dementia, 18.6 percent receive hospice care in a given year—a higher percentage than other chronic conditions. Among seniors in hospice care, nearly 1 in every 5 has a primary hospice diagnosis of Alzheimer's or other dementia.
- In the Veterans Administration health care system, 61.4 percent of dementia patients receive palliative care consultations in the last 90 days of life.
- Nearly half of all people with dementia die in hospice care.

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**The availability of palliative and hospice care is growing, but the need is growing faster—and the quality of the care remains a concern.**

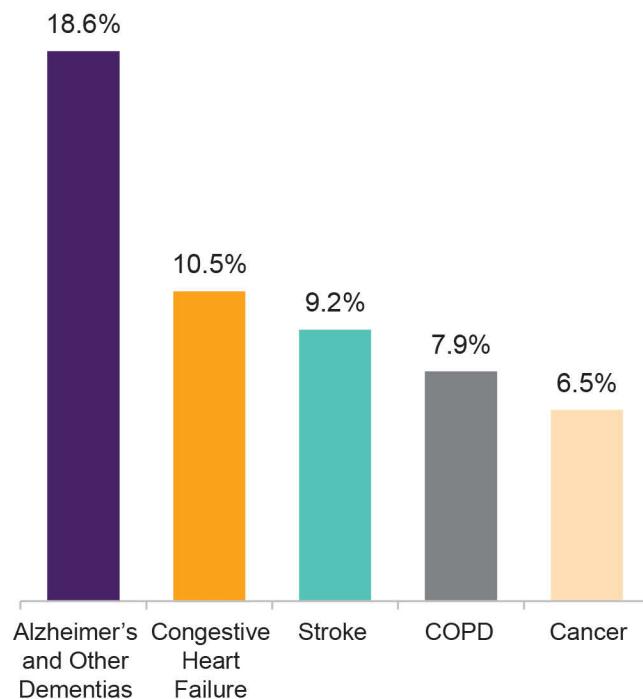
- In 2000, less than one-quarter of U.S. hospitals had a palliative care program. By 2013, that had increased to three-quarters.
- Hospice care is now available in nearly three-quarters of surveyed nursing homes, but less than half of surveyed nursing homes report having some sort of palliative care program.
- Of those nursing homes with a palliative care program, only 42 percent include consultation by a physician certified in hospice/palliative care, and only 28 percent had a designated palliative care director.
- In the 2014-15 academic year, only 265 physicians were trained in hospice and palliative medicine by accredited programs. An expert Task Force concluded that 6,000 more full-time health care professionals are needed to serve current needs in hospice and palliative care programs.

**To increase the availability and quality of care, the Palliative Care and Hospice Education and Training Act (PCHETA) (S. 693 / H.R. 1676) would:**

- Establish palliative care and hospice workforce training programs for doctors, nurses, and other health professionals.
- Create a national education and awareness campaign to inform patients, families, and health professionals about the benefits of palliative care and available services and supports.
- Enhance research on improving the delivery of palliative care.

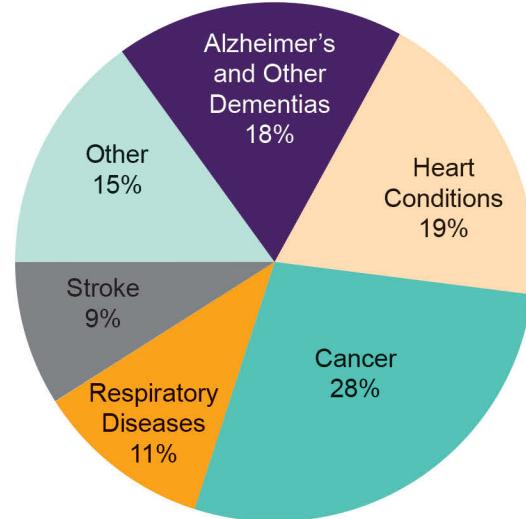
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**Percentage of Seniors with Specified Condition Who Are Receiving Hospice Care, 2014**




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**Hospice Users, by Primary Hospice Diagnosis, 2015**



# PCHETA BACKGROUND

*ASK: Please cosponsor the Palliative Care and Hospice Education and Training Act (S. 693/H.R. 1676), which would ensure an adequate, well-trained palliative care workforce through workforce training, education and awareness, and enhanced research.*

## Background

The Alzheimer's Association strongly supports the bipartisan Palliative Care and Hospice Education and Training Act (PCHETA), which was reintroduced by Representative Eliot Engel (D-NY-16) and Representative Tom Reed (R-NY-23) in the U.S. House of Representatives and Senator Tammy Baldwin (D-WI) and Senator Shelley Moore Capito (R-WV) in the Senate.

## Making the Case for PCHETA

### **Palliative and hospice care are important services for people with Alzheimer's and other dementias.**

- » A recent study shows that nursing home residents with dementia who receive palliative care at the end of life, compared with those who do not receive such care, are up to 15 times less likely to die in a hospital and nearly 2.5 times less likely to have a hospitalization in the last 30 days of life and up to 4.6 times less likely to visit the emergency room in the last week of life.
- » Of all people living with dementia, 18.6 percent are currently in hospice care – a higher percentage than other chronic conditions – and one in every five seniors in hospice care

has a primary hospice diagnosis of Alzheimer's or other dementia.

- » Nearly half of all people with dementia die in hospice care.

**To address these issues, PCHETA would increase the palliative care and hospice workforce by establishing training programs for doctors, nurses, and other health professionals through:**

- » Grants to medical schools and teaching hospitals to train physicians to teach palliative medicine.
- » Career development awards for hospice and palliative medicine faculty.
- » Workforce development fellowships in palliative medicine for doctors, nurses, social workers, chaplains, and other allied health professionals.
- » Career incentive awards for nurses, clinical social workers, and pharmacists who agree to teach or practice palliative medicine for a period of five years.
- » Preferences in existing programs that emphasize nurse retention and nurse education, practice and quality in hospice, and palliative medicine.

**PCHETA would also increase awareness of palliative care and hospice by launching a national campaign to:**

- » Inform patients, families and health professionals about the benefits of palliative care.
- » Create and disseminate information about available palliative care services.

**Finally, PCHETA would enhance palliative care research by:**

- » Directing the National Institutes of Health (NIH) to use existing authorities and funds to develop a research strategy in palliative care to address quality of care and quality of life for patients with serious illnesses.
- » Expanding research at the NIH for palliative care, pain management and symptom management.
- » Establishing a program to educate patients and caregivers about the palliative care delivery model.
- » Creating an education and training program for allied health professionals, including nurses, nursing assistants, social workers, professional chaplains and patient navigators.

# PCHETA TALKING POINTS



## Share Your Story

If you have used these services, share a story highlighting your family's experience with palliative care and hospice care.

Talk about how access to well-trained palliative care professionals could have benefited you and your family.

## Frequently Asked Questions

During the course of your meetings with members of Congress and their staffs, you may encounter some common questions regarding the Palliative Care and Hospice Education and Training Act (PCHETA). We have addressed some of these common questions below.

### Q. What is palliative care?

#### Suggested Response:

- » Palliative care is a team-based approach that focuses on relieving symptoms and stress and supporting the best possible quality of life for patients, their caregivers and their families.
- » Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work with a patient's other doctors to provide an extra layer of support.
- » Palliative care is appropriate at any age and any stage of a serious illness. Palliative services can be applied from the point of diagnosis through the continuum of the disease.

### Q. What is hospice care?

#### Suggested Response:

- » Like palliative care, hospice care focuses on managing and easing symptoms, reducing pain and stress, and increasing comfort. However, hospice care is generally provided at the end of life.
- » People with Alzheimer's and other dementias rely heavily on hospice at the end of life. Of all people living with dementia, 18.6 percent are currently in hospice care – a higher percentage than other chronic conditions.
- » Nearly half of all people with dementia die in hospice care.

### Q. How much would PCHETA cost?

#### Suggested Response:

- » The bill has not been scored by the Congressional Budget Office (CBO), and there is no cost estimate for the bill. However, the Alzheimer's Association will continue to work with the bill's sponsors to determine the impact this bill would have on federal spending.

# PCHETA TALKING POINTS

## Q. Are other organizations supportive of the legislation?

### Suggested Response:

- » Yes. PCHETA is supported by the Patient Quality of Life Coalition (PQLC), which was formed to advance the interests of patients and families facing serious illness. Over 40 health and advocacy organizations support this bill, including the American Heart Association and the American Cancer Society Cancer Action Network.

## Q. What changes were made to PCHETA since the 114th Congress?

### Suggested Response:

- » The legislation is the same with the exception of one small technical correction, which was made to clarify that eligibility requirements for the education and training grant programs proposed in the legislation are consistent with all funding requirements in the Public Health Service Act.
- » A member of the Alzheimer's Association's Federal Affairs team would be happy to talk with you about the technical change made to PCHETA.



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# 2018 STATE POLICY PRIORITIES

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

## 1 Implement and update state Alzheimer's disease plans

Since 2007, almost every state has developed a State Alzheimer's Disease Plan to address the growing economic and social impact of the disease. These comprehensive plans identify critical issues, recommend solutions, and create a roadmap to guide a state's development into a dementia-capable state. State legislatures and state agencies must fully implement the recommendations included in their state's Alzheimer's disease plan and revisit and re-publish their plans every three to five years to ensure they are kept up to date and account for current needs and recent developments.

## 2 Improve dementia training

People with Alzheimer's disease deserve quality care throughout the course of the disease – and they deserve to receive it from knowledgeable professionals across the care continuum. All individuals employed to provide care in residential, home, and adult day settings must be properly trained in dementia care. Yet training standards vary widely by state. For example, less than

half of all states require dementia training for staff of nursing homes, and less than one-fifth of states require it for adult day staff. As the number of people living with Alzheimer's and other dementias increases, states must have adequate dementia-training laws to equip workers across the care continuum with the ability to provide person and family-centered care, communicate effectively with persons with dementia, and address specific and unique aspects of care and safety for people with dementia.

## 3 Increase early detection and diagnosis of Alzheimer's

Fewer than half of all people who have been diagnosed with Alzheimer's disease, or their caregivers, are aware of the diagnosis. Early detection and diagnosis — and knowledge of the diagnosis — are essential to ensuring the best medical care and outcomes for those affected by the disease. *Healthy People 2020* has set the goal of increasing diagnosis awareness among individuals with Alzheimer's or their caregivers.

## 4 Educate the public about risk reduction

There is a growing scientific consensus that regular physical activity, management of certain cardiovascular risk factors (such as diabetes, smoking, and hypertension) and avoidance of traumatic brain injury can reduce the risk of cognitive decline. Studies show these factors may also reduce the risk of dementia. Especially in the absence of a disease-modifying treatment, public health action must be taken to increase public awareness and education about known and potentially modifiable risk factors of cognitive decline and dementia.

## 5 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 POLICY 101

State policy is vital to the work the Association does to meet the care and support 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; determine spending for state long-term care services; and control Medicaid spending, and in some cases, eligibility and scope of benefits. All of these can have a direct effect on families for whom the Association provides care and support.

## How to Work With State Legislatures

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 times 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.

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.

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, and Montana, do not meet every year.

## Attend Your State's Alzheimer's State Advocacy Day

State advocacy days provide an opportunity to increase the Association's presence in the state capital and to build relationships with state policymakers. This event brings advocates together to draw attention to a critical policy issue impacting those living with Alzheimer's and to offer solutions to state policymakers.

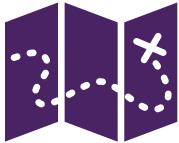
Alzheimer's Association chapters in every state host an annual Alzheimer's State Advocacy Day.

**Connect with your local Alzheimer's Association chapter policy staff and visit the chapter website at [alz.org/findus.asp](http://alz.org/findus.asp).**



# 2018 PUBLIC HEALTH ISSUES

The inclusion of Alzheimer's disease in *Healthy People 2020* — the nation's health prevention and promotion goals for the next decade — confirms that Alzheimer's is a pivotal public health issue, requiring bold action before the crisis worsens.



## Implement the Public Health Road Map

In 2013, the Centers for Disease Control and Prevention (CDC) and the Alzheimer's Association released *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018* to advance cognitive health as a vital, integral component of public health. The Road Map has a menu of 35 specific actions that public health agencies can undertake to promote cognitive functioning, address cognitive impairment, and help meet the needs of caregivers.

Examples include:

- » Fielding the Cognitive and Caregiver Modules of the *Behavioral Risk Factor Surveillance System (BRFSS)* and then using the data to inform, improve and enhance public health programming.
- » Collaborating in the development, implementation and maintenance of state Alzheimer's disease plans.
- » Conducting state or local needs assessments related to Alzheimer's and other dementias.
- » Placing links on public health agency websites to local, state, and national dementia resources.



## Increase early diagnosis of Alzheimer's

Fewer than half of all people who have been diagnosed with Alzheimer's disease, or their caregivers, are aware of the diagnosis. Early detection and diagnosis — and knowing of the diagnosis — are essential to ensuring the best medical care and outcomes for those affected by the disease. *Healthy People 2020* has set the goal of increasing the percentage of individuals with the disease or their caregivers who are aware of the diagnosis.

Actions that must be taken to increase early diagnosis include:

- » Educating the public and the medical community about the warning signs of possible dementia and the benefits of early diagnosis.
- » Educating health care professionals on the importance of discussing memory issues with their adult patients and the use of validated cognitive assessment tools.



## Educate the public about risk reduction

There is a growing scientific consensus that regular physical activity, management of certain cardiovascular risk factors (such as diabetes, smoking, and hypertension), and avoidance of traumatic brain injury can reduce the risk of cognitive decline. Studies show these factors may also reduce the risk of dementia. Especially in the absence of a disease-modifying treatment, an effort must be undertaken to increase public awareness and education about known and potentially modifiable risk factors of cognitive decline and dementia. Risk reduction messages for preserving cognitive health should be integrated into public health policies, campaigns, strategies and action plans.

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

# AFTER FORUM

While each individual will have a unique experience interacting with elected officials and their staff, we hope your experience at the 2018 Advocacy Forum is a productive and enjoyable one.

Your efforts on behalf of yourself, the Alzheimer's Association, AIM and all 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 Advocacy Engagement Planner for other suggested activities throughout the year.



## Post-Forum Checklist:

- Report your meeting(s) in AIM ([alzimpact.org](http://alzimpact.org)).
- Send a "Thank You" letter, email or Tweet to your member of Congress.
- Debrief 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.
- Download the ALZ Advocacy app for Android and iOS at [alz.org/advocateapp](http://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](http://alz.org/forum).
- Share your Forum experience with local media outlets (newspapers, blogs) via a Letter to the Editor.
- Add [info@alz.org](mailto: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.

# ADVOCACY ENGAGEMENT PLANNER

Working with your local Alzheimer's Association staff and fellow advocates, use the suggested activities to plan your engagement for the remainder of the year.

1. Participate in a Coffee with Congress, town hall or other local Alzheimer's Association advocacy event.
2. Share an AIM action alert with 5 friends.
3. Ask candidates for public office and/or elected officials to address Alzheimer's at campaign events, community gatherings or holiday events.
4. Write a letter to the editor.
5. Help plan your state advocacy day with local staff.
6. Send a Tweet to an elected official.
7. Urge friends, family and others in your community to get involved in the Alzheimer's Impact Movement.
8. Get involved with your local Walk to End Alzheimer's event and assist with advocate recruitment efforts.
9. Engage local media outlets and share your story. Urge viewers, listeners and readers to contact their local officials.
10. Meet with an elected official or drop off materials at their local office.

A teal notepad with a white header section containing the word "OCT" in a black box.

A purple notepad with a white header section containing the word "NOV" in a black box, and a large white body section with ten horizontal lines for writing.

A yellow notepad with a white header section containing the text 'DEC' in a black box, and a white body section with five horizontal lines for writing.

# GET CONNECTED AT ALZIMPACT.ORG



NEARLY ONE IN EVERY FIVE MEDICARE DOLLARS IS SPENT ON PEOPLE WITH ALZHEIMER'S OR ANOTHER DEMENTIA

Support the #BOLDAlzheimersAct

## Your Gateway to Alzheimer's Advocacy



### Learn

Find fact sheets, guides, sample materials and upcoming events in your personalized "My Advocacy Resources" section. [alzimpact.org/resources](http://alzimpact.org/resources)



### Connect

Learn about your legislators and connect with your Alzheimer's Congressional Team. [alzimpact.org/congress/search](http://alzimpact.org/congress/search)



### Act

Take action on AIM/Alzheimer's Association federal policy priorities and get signed-up for mobile alerts. [alzimpact.org/take\\_action/act\\_now](http://alzimpact.org/take_action/act_now)



### Report

From your Forum meeting to a simple tweet, please report all your legislative interactions so your team and our staff are in the loop. [alzimpact.org/action](http://alzimpact.org/action)

## Download your AIM Power of Ten Referral Cards



[alzimpact.org/join](http://alzimpact.org/join)



[alzimpact.org/join](http://alzimpact.org/join)

PLEASE USE MY REFERRAL CODE

PLEASE USE MY REFERRAL CODE

### Power of Ten

**Have your friends joined AIM?**

**Take the Power of Ten Challenge!**

The Alzheimer's Impact Movement (AIM) is the advocacy arm of the Alzheimer's Association. With help from AIM and its members, research funding has more than tripled in five years!

Persuading 10 friends to join AIM for just \$20 is one of the best ways you can influence how leaders in Washington and in state capitals address the Alzheimer's crisis.

List 10 friends you could ask to join AIM:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_
6. \_\_\_\_\_
7. \_\_\_\_\_
8. \_\_\_\_\_
9. \_\_\_\_\_
10. \_\_\_\_\_

Find your personal Power of Ten Referral code, instructions, incentives and other tools in the Power of Ten Challenge Kit, available at: [alzimpact.org/recruit](http://alzimpact.org/recruit).

# LETTER TO THE EDITOR TALKING POINTS

The following talking points can be used to help you write a personal and compelling letter to the editor for placement in your local paper. As always, please coordinate your efforts with your local chapter to avoid duplication. Note: Please check to see if your member is a cosponsor of the **BOLD Infrastructure Act** and/or **PCHETA** and adjust the language before submitting. And, send a copy of your placed *LTE* to your lawmakers and report it in [alzimpact.org](http://alzimpact.org).

## Compelling Opening Suggested Talking Points

(choose or create your own)

- » There are more than 5 million Americans living with Alzheimer's, including **NUMBER** here in **STATE**. I am one of those people.
- » There are more than 15 million Americans caring for someone with Alzheimer's or another dementia, including **NUMBER** here in **STATE**. I am one of those people.
- » There are more than five million Americans living with Alzheimer's disease and more than 15 million Alzheimer's caregivers. As an Alzheimer's **ADVOCATE OR AMBASSADOR**, it is my honor to represent them.
- » Share a few sentences of your story and why you are an advocate.
- » I am **going to/just returned** from Washington, D.C. where more than 1,000 Alzheimer's advocates from across the nation **will attend/attended** the Alzheimer's Association AIM Advocacy Forum.
- » While in Washington I **met/will meet** with **MEMBER** to explain why Congress must continue to take action against Alzheimer's.
- » I **will/I asked** **MEMBER** to support **[Insert one of the three priorities]**.

## Statistics to Make the Case Talking Points

(choose a few or highlight others)

- » Alzheimer's is the only leading cause of death in the U.S. without a way to prevent, cure or even slow its progression.
- » According to the Alzheimer's Association 2018 *Alzheimer's Disease Facts and Figures*, by 2050, the total cost of care for Alzheimer's is projected to increase to more than \$1.1 trillion.
- » Alzheimer's is the most expensive disease in the country costing \$277 billion in 2018, including \$186 billion in costs to Medicare and Medicaid.
- » It is only through adequate funding and a strong implementation of the *National Plan to Address Alzheimer's Disease* that we will meet its goal of preventing and effectively treating Alzheimer's by 2025.

## Ending Call to Action Talking Points

- » Please join me in urging **MEMBER** to support **[Insert one of the three priorities]**.
- » To learn more about this disease and how you can join the fight to end Alzheimer's visit [alz.org](http://alz.org).



# LETTER TO THE EDITOR WRITING TIPS

## Tips for Writing Printable Letters to the Editor

Writing a letter to the editor (LTE) is an effective way to call attention to an issue.

Here are tips for writing a LTE that gets published and read:

- 1. Know the rules.** Do your homework about how to submit a letter and what information you need to include in order to get it printed. Usually this information is located on the opinion page of the newspaper or you can find it on the newspaper's website. Pay attention to word count submission requirements and instructions on the best way to submit the document.
- 2. Make it relevant.** Following these tips, we have provided LTE message points and blocks of suggested text for your use. Tailor and modify them with your personal details so that it becomes a piece reflecting your authentic voice, while always staying consistent with Alzheimer's Association messaging.
- 3. Keep it brief.** Most letters to the editor should be 200 words or less. Any longer and it may not get printed.
- 4. Highlight local statistics.** Include relevant local and/or state information – the number of people with Alzheimer's in your state, the projected number of individuals age 65 or older with Alzheimer's in your state, mortality data, costs related to caregiving in your state, etc. This information localizes the impact and can increase interest in publishing the letter. Alzheimer's-related information from your state can be found in the *Alzheimer's Association Facts and Figures report*.
- 5. Be clear.** While you may be an expert on this issue, not everyone knows about it. Avoid jargon or acronyms that are not common. Have someone proofread the document before you send it.
- 6. Use language cues to emphasize your point.** For instance, conclude with "The important thing is..."
- 7. Don't overlook neighborhood weeklies, smaller newspapers and local websites and blogs.** These media outlets are intensely important within the area they're published and they also may have more room for letters than a bigger publication.
- 8. Include a call-to-action or solution.** Include information about what people can do to help. For example: "Visit ALZ.org to learn more about this year's *Alzheimer's Association Facts and Figures report*," or "Visit ALZ.org to get involved with the fight against Alzheimer's."
- 9. Be passionate, but not poisonous.** We appreciate your passion about the issue (and so will the editors), but we also implore you to be respectful in your commentary.
- 10. Consider the online editorial page.** Many newspapers are moving to just online versions or have an extended letters section in their online versions. Research your local news media outlets to see if there is a way to be included in these sections as well.

## PHONE TO ACTION ALERT

### SIGN UP TO ACT

Text **AIM** to  
**52886**  
to join the fight



Message and Data Rates May Apply. Reply STOP to optout, HELP for help.

## NOTES

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# ADVOCACY FORUM 2018

alzheimer's  association®



## ALZHEIMER'S ASSOCIATION Public Policy Office

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