



2021 ADVOCATES GUIDE





WELCOME



Dear Alzheimer's Advocate,

Thank you for your continued commitment in the fight to End Alzheimer's and all other dementia.

2020 was truly unprecedented and our community faced many challenges. Yet, because of your perseverance and willingness to adapt your advocacy, we secured tremendous public policy advancements at the federal and state level. From your homes across the country you remained engaged with policymakers in Congress, in state capitals and on the campaign trail.

This year marks the 10 year anniversary of the National Alzheimer's Project Act (NAPA) being signed into law. This landmark legislation has been a catalyst for changing the way our nation addresses Alzheimer's. Since NAPA became law, and with the release of the first National Plan to Address Alzheimer's Disease, we have

secured a seven-fold increase in Alzheimer's and dementia research funding at the National Institutes of Health (NIH), the BOLD Infrastructure for Alzheimer's Act, improved access to care and support for people living with dementia regardless of their age, grew support for the decision by Medicare to cover care planning, and so much more. We've also worked with state governments to develop state Alzheimer's plans and advance public health initiatives at the state and local level.

After so many successes, it's easy to think these victories are commonplace — but they're not.

They're because of each one of you. Your work is the reason progress is happening on Capitol Hill and across the nation. Thank you.

BUT WE KNOW, MORE WORK REMAINS.

In this Advocates Guide, you'll find everything you need to make the most of your year around advocacy efforts, including detailed information about our policy priorities, and tips and resources on how to successfully connect with elected officials. We'll be updating this guide throughout the year as our policy priorities are introduced in Congress. And, be sure to follow our social media accounts and use #ENDALZ to continue the conversation online.

Working together we're confident 2021 will be another remarkable year for Alzheimer's and dementia advocacy. Thank you for joining us in the fight.

Sincerely,
The Alzheimer's Association
AIM Public Policy Team



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2021 ALZHEIMER'S DISEASE FACTS AND FIGURES

DISCRIMINATION

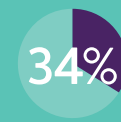
is a barrier to Alzheimer's and dementia care. These populations reported discrimination when seeking health care:



of Black Americans



of Native Americans



of Asian Americans



of Hispanic Americans



1 IN 3

seniors dies with Alzheimer's or another dementia



MORE THAN 6 MILLION

Americans are living with Alzheimer's

Alzheimer's and dementia deaths have increased

16%

during the COVID-19 pandemic



OVER 11 MILLION

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



These caregivers provided an estimated 15.3 billion hours valued at nearly

\$257 BILLION



It kills more than

BREAST CANCER



PROSTATE CANCER

COMBINED

Between 2000 and 2019, deaths from heart disease have

DECREASED 7.3%

while deaths from Alzheimer's disease have

INCREASED 145%

In 2021, Alzheimer's and other dementias will cost the nation

\$355 BILLION



By 2050, these costs could rise to more than

\$1.1 TRILLION



FACTSHEET

MARCH 2021

alzimpact.org

2021 Alzheimer's Disease Facts and Figures

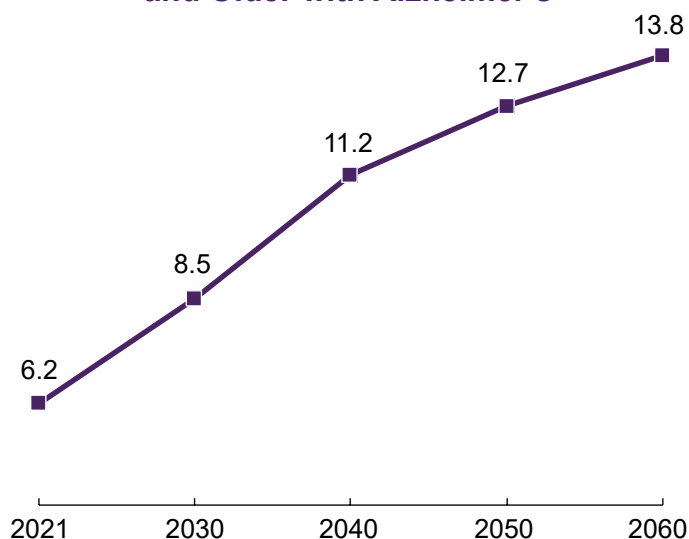
The number of Americans living with Alzheimer's is growing — and growing fast.

- Today, more than 6 million Americans are living with Alzheimer's — 1 in 10 people aged 65 and older.
- The number of people living with Alzheimer's is expected to more than double to nearly 13 million by 2050.

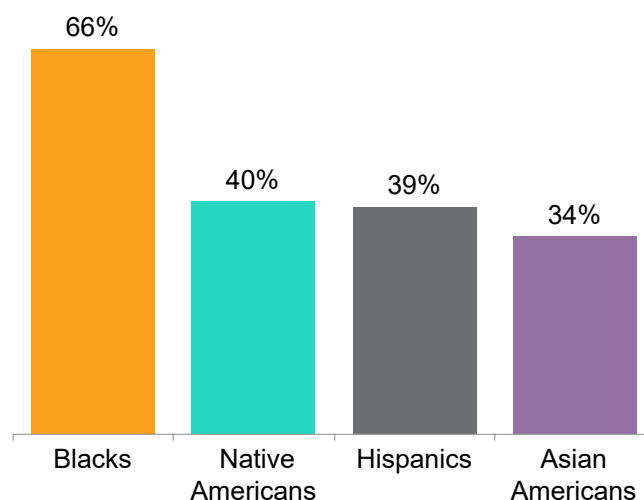
However, the burden of Alzheimer's is not equally shared. Non-White populations experience barriers when accessing dementia care.

- Blacks are about two times more likely than Whites to have Alzheimer's and other dementias. Similarly, Hispanics are about one and one-half times more likely than Whites to have Alzheimer's and other dementias.
- Yet, two-thirds of Blacks believe that it is harder for them to get excellent care for Alzheimer's, along with 40% of Native Americans and 39% of Hispanics.
- Fewer than half of Blacks and Native Americans feel confident they have access to providers who understand their ethnic or racial backgrounds.
- Additionally, 62% of Blacks believe that medical research is biased against people of color. This belief is also held by more than a third of Asian, Hispanic, and Native Americans.

Millions of Americans Aged 65 and Older with Alzheimer's



Percentage of Adults Who Believe Their Race/Ethnicity Will Affect the Quality of Dementia Care



The growing number of people living with Alzheimer's is placing a huge strain on the health care system.

- In 2021, the direct costs to American society of caring for those with Alzheimer's will total an estimated \$355 billion, with \$239 billion of it (67%) paid by Medicare and Medicaid.
- Average per-person Medicare spending for those with Alzheimer's and other dementias is more than three times higher than average per-person spending across all other seniors. Medicaid payments are 23 times higher.
- Unless something is done, in 2050, Alzheimer's will cost more than \$1.1 trillion (in 2021 dollars).

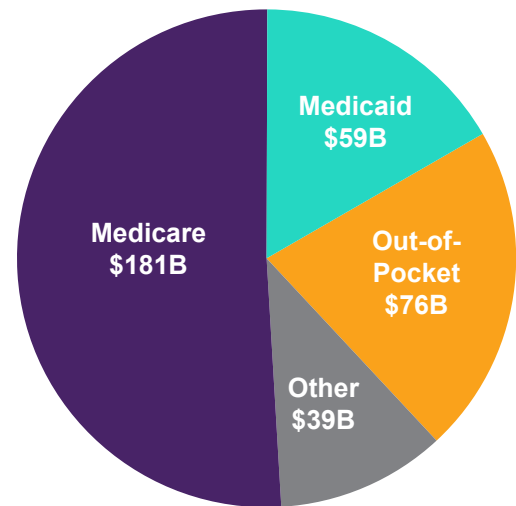
Alzheimer's is not just memory loss. Alzheimer's kills.

- In 2019, 121,499 people in the United States died from Alzheimer's disease, making it 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 145% from 2000 to 2019 while deaths from other major diseases (including heart disease, stroke and HIV/AIDS) decreased.
- Preliminary data show that in 2020, during the COVID-19 pandemic, there were approximately 42,000 Alzheimer's and dementia deaths in excess of the average.

Facts in Your State

The 2021 *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](https://www.alz.org/facts).

2021 Costs of Alzheimer's = \$355 Billion

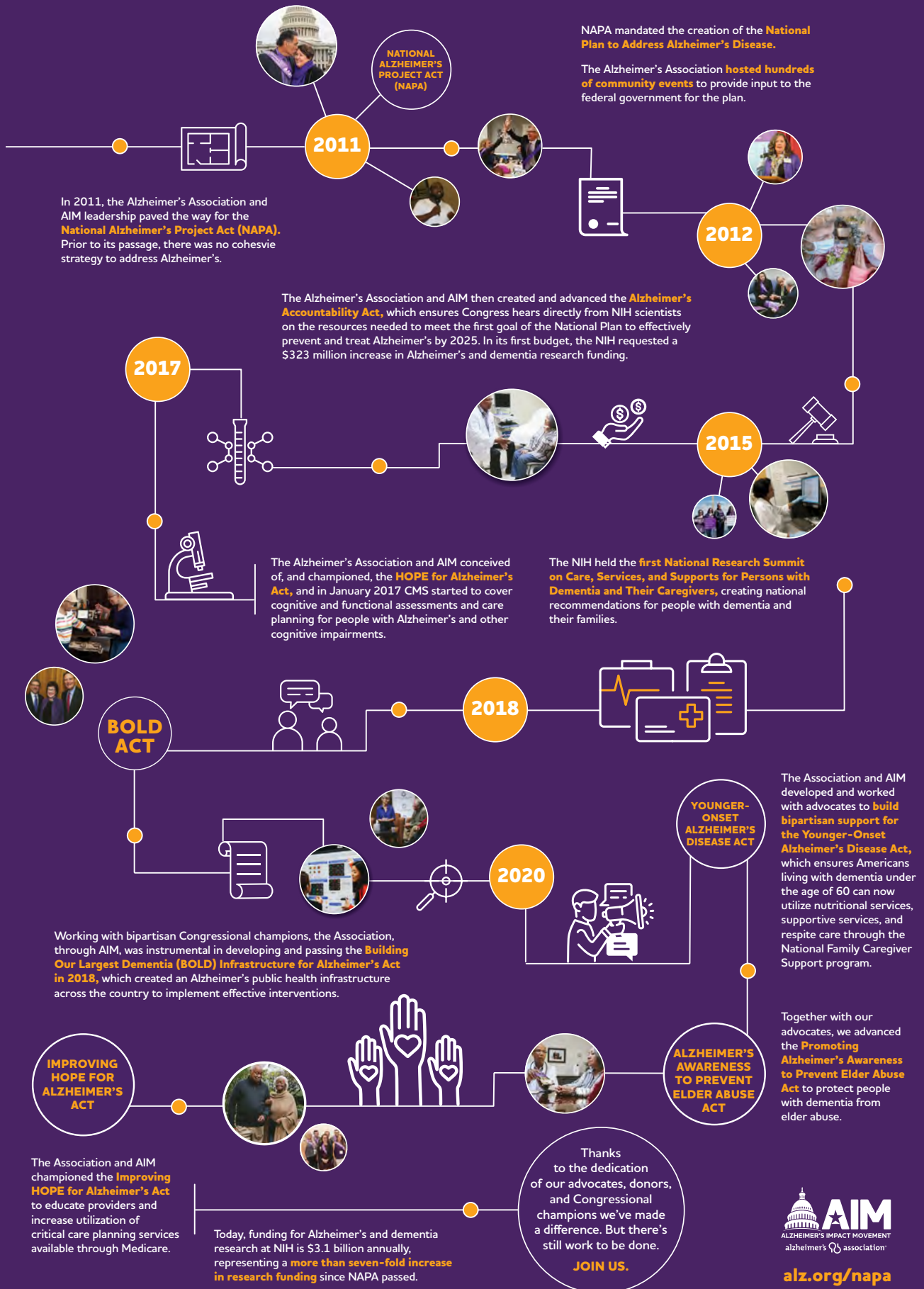


Alzheimer's also places a substantial burden on families.

- In 2020, family members and friends of individuals living with dementia provided unpaid care valued at nearly \$257 billion.
- On average, each dementia caregiver today spends 20% more time providing care than a dementia caregiver did a decade ago. This is the equivalent of nearly six more full work weeks of unpaid care each year.
- Of the total lifetime cost of caring for someone with dementia, 70% 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 expenses — is nearly twice as high as that incurred by caregivers of people without dementia.
- Nearly three-fourths of dementia caregivers report that they are concerned about maintaining their own health since becoming a caregiver.

10TH ANNIVERSARY

National Alzheimer's Project Act (NAPA)





TIPSHEET: SPARK SOCIAL MEDIA CONVERSATIONS

Social networks enable direct interaction with policymakers, as most run (or at least monitor) their own social media accounts to gather feedback from constituents. With just a handful of simple actions you can make a big difference in the fight to end Alzheimer's.



TAGGING

Mentioning or Tagging is an easy way to engage legislators online. On most major social networks, simply include their "handle" (i.e. @SenatorName) in your post.



RETWEETING & COMMENTING

Reply and comment on policymakers' posts to raise the issue of Alzheimer's. You can also share their posts adding your thoughts. Share posts from AIM, your chapter or fellow advocates and tag your legislator to bring them into the conversation.



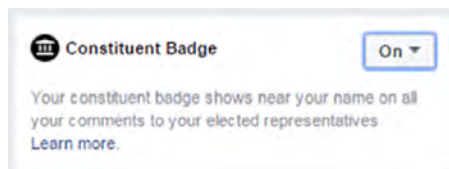
#HASHTAGS

Hashtags link together a conversation and help you find relevant information. One commonly used example is: **#ENDALZ**. Please make sure the hashtag matches the message you are sending.



REMEMBER THE "RULE OF THREE"

Mentions, tags and hyperlinks are all interactive and clickable parts of a social media post or Tweet. It is best to include no more than three in a single post. Including too many can distract from your primary message.



IDENTIFY YOURSELF AS A CONSTITUENT

Legislators want to hear from their constituents online. Visit **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** 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!



GET LINKEDIN

Elected officials aren't your only audience. You can connect with legislative staff, local influencers, other advocates and community allies via your professional network. You can share AIM posts, your own letters-to-the-editor and relevant Alzheimer's information.



TIPSHEET: SPARK SOCIAL MEDIA CONVERSATIONS



SHARE THE PICTURE

Images and videos increase the likelihood your post will be noticed. Tag any individuals, organizations and locations featured in your photo or video. If it includes an elected official or their staff, be sure to get their permission before posting. Post multiple photos together as an album.



BROADCAST YOURSELF

Consider sharing a “live” video 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 video clips so you can share highlights later for those who missed it.



MEET VIRTUALLY

Remote video calls and virtual meetings have replaced many in-person interactions. Use Zoom, Skype, FaceTime and other tools to hold meetings with policymakers and fellow advocates.

ADVOCACY BINGO

Have some fun and engage on social media by completing the Advocate Bingo card below. Be sure to use **#ENDALZ** in your posts. Mark your card when you take one of the actions.

Take a selfie at a local landmark and share it	Comment on another advocate's post	Post your “Why I’m an Advocate” photo, story or video	Use an Alzheimer’s related image as your Zoom or video background	Ask your social network followers to take action.
Tag your local Alzheimer’s Association Chapter in a post	Tweet at both of your U.S. Senators	Make an “ask” on one of our priorities via a video	Show us your purple pride (i.e. your wardrobe)	Retweet or share a post from the Alzheimer’s Association
Comment on an AIM or Association YouTube video	Send an email to friends/ family urging them to take action	FREE SPACE		Share a 1 minute “Why I’m an Advocate” video
Be zany. Try using Boomerang, animation or silly filter.	Follow 3 other advocates NOT from your state	Comment on Your U.S. Senator(s) Facebook Page or tag them in a post	Comment on or reply to one of AIM’s posts	Text ALZ to 52886 and take action
Take a pic with an #ENDALZ sign or paddle	Share a post from alz.org/blog or alzimpact.org/blog	Have a pet? Show us how they’re taking action	Tag one of the presenters or featured speakers in a post	Share a group screenshot from a Zoom or video conference



LEGISLATIVE MEETING TIPS

Even in these times of virtual meetings, it's important to make sure you're prepared for meetings with elected officials.



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 disagree with your message may support our future efforts. It's important not to burn any bridges.

BE BRIEF

Virtual burnout is real and something we all can experience from time to time. Try to keep your story short and to the point.



KEEP IT SIMPLE

Don't be too technical, too detailed or too complex. 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 to lead the meeting.

NEVER TELL A 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. The safest phrase to remember is, "I'm not sure, but I can follow up with the policy team at the Alzheimer's Association to get more information."

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 and let them know you intend on following up.

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. Use #ENDALZ to connect to other Alzheimer's Advocates.

REPORT YOUR ACTIVITY

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

ALZIMPACT.ORG



LEGISLATIVE MEETING CHECKLIST

Below are some suggested ways to successfully plan a group meeting with elected officials.

ASSIGN ROLES AND ASSIGNMENTS

- » Who is responsible for emailing materials before or after the meeting?

- » Who is going to handle introductions? Ex. Who we are, why we're here?

- » 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/screenshot to be taken?

LOGISTICS

- » Have the meeting time and virtual platform been confirmed?
- » Do all attendees have the legislative office's contact information?

PRE-MEETING

- » Are all meeting attendees present and accounted for?
- » Did you confirm meeting roles over email prior to the meeting?

POST-MEETING

- » Who will post a photo from the meeting to Twitter and Facebook?

- » Who will submit the meeting report to alzipact.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?



2021 FEDERAL POLICY 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

BUILD A PATH TO BETTER DEMENTIA CARE

Caring for an individual with Alzheimer's or another dementia poses unique challenges. Comprehensive dementia care has been shown to reduce costs while providing better quality care. Unfortunately, dementia care management programs have not developed within the current Medicare fee-for-service system. The bipartisan *Comprehensive Care for Alzheimer's Act (S. 1125 / H.R. 2517)* would ask the Center for Medicare and Medicaid Innovation (CMMI) to test a different payment structure for dementia care management. This important bill has the potential to streamline today's complicated health care maze for people living with dementia and their caregivers.

2

SUPPORT EQUITY IN ALZHEIMER'S CLINICAL TRIALS

Alzheimer's and other dementia disproportionately affect older Black and Hispanic Americans compared to older Whites. In fact, Black Americans are twice as likely to develop Alzheimer's, and Hispanic Americans are one and a half times more likely to develop the disease. Yet much of the Alzheimer's research to date has not included sufficient numbers of Black, Hispanic, Asian or Native Americans to be representative of the U.S. population. The underrepresentation of these populations not only hinders the ability of researchers to understand these health disparities, it also restricts their knowledge of how an approved therapy or diagnostic may affect the populations most likely to need the treatment. The bipartisan *Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act (H.R. 3085 / S. 1548)*, would increase the participation of underrepresented populations in Alzheimer's and other dementia clinical trials by expanding education and outreach to these populations, encouraging the diversity of clinical trial staff and reducing participation burden, among other priorities.



2021 FEDERAL POLICY 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.

3

INCREASE THE COMMITMENT TO ALZHEIMER'S RESEARCH AND PUBLIC HEALTH RESPONSE

More than 6 million Americans are living with Alzheimer's, and by mid-century, the number of people with the disease is set to nearly triple. Already the most expensive disease in America with costs reaching an estimated \$355 billion in 2021, these costs are projected to more than quadruple to \$1.1 trillion by mid-century, with two-thirds paid by Medicare and Medicaid.

- » Consistent with the *National Plan to Address Alzheimer's Disease*, Congress has bolstered support for research funding at the National Institutes of Health (NIH). Nevertheless, current funding levels continue to fall short of the total funding scientists and the U.S. Advisory Council on Alzheimer's Research, Care, and Services believe is needed to meet the goal of finding a treatment or cure for Alzheimer's and other dementias by 2025. Congress must continue its commitment to the fight against Alzheimer's and other dementias by increasing funding for Alzheimer's research by an additional \$289 million in fiscal year 2022.
- » The bipartisan *Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L. 115-406)* directs the Centers for Disease Control and Prevention (CDC) to strengthen the public health infrastructure across the country by implementing effective Alzheimer's interventions focused on public health issues such as increasing early detection and diagnosis, reducing risk, and preventing avoidable hospitalizations. The *BOLD Infrastructure for Alzheimer's Act* will accomplish this by establishing Alzheimer's and Related Dementias Public Health Centers of Excellence; providing funding to state, local, and tribal public health departments; and increasing data analysis and timely reporting. To ensure the law's successful implementation, Congress must fully fund the \$20 million authorized in the law for CDC in fiscal year 2022.

4

SUPPORT ALZHEIMER'S CAREGIVERS

Although often rewarding, the intense responsibilities of providing care for someone living with dementia often take a toll on the caregiver. Providing that care can be an emotionally, physically and financially draining role. Yet as a nation, we haven't done enough to support the 11 million Americans providing this unpaid care. The bipartisan *Alzheimer's Caregiver Support Act (S. 56/H.R.1474)* would provide much needed relief for our nation's caregivers. *The Alzheimer's Caregiver Support Act* would provide grants to expand training and support services for unpaid caregivers of people living with Alzheimer's disease and other dementia. These grants would cover valuable training and services including caregiver support groups, group education and skills-training sessions.

FACTSHEET

APRIL 2021

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Comprehensive Care for Alzheimer's Act

Caring for an individual living with Alzheimer's or another dementia poses unique challenges.

- More than 95% of individuals with dementia have one or more other chronic conditions, the management of which is complicated by an individual's cognitive impairment.
- Individuals with dementia rely heavily on family members to provide a large amount of care, which is often intrusive and exhausting.
- Too often, those with Alzheimer's and their caregivers are forced to fend for themselves in the complicated maze of the health care and social support systems.

Dementia care management can ease these challenges, improving quality of care and reducing costs.

- Dementia care management is a model of care that is proven to reduce health care use and costs and to improve the quality of life for individuals living with dementia and their families
- Dementia care management enables individuals to more seamlessly navigate health care and social support systems and to obtain more timely access to care.
- Elements of dementia care management include care coordination and navigation, management of chronic conditions, and caregiver education and support.

However, a change in the payment structure is necessary to enable dementia care management.

- Under the current system, many practices cannot afford the upfront costs of developing, implementing, and sustaining a dementia care management program.
- Instead of paying a fee for each specific service, providers should receive an annual per-patient payment for all services provided under the program, including important services not otherwise reimbursed by Medicare.
- This structure would allow dementia care management programs to be financially feasible for health care providers and practices; especially for smaller practices, rural practices, and inner-city community health centers.

The Comprehensive Care for Alzheimer's Act (S. 1125 / H.R. 2517) would ask the Center for Medicare and Medicaid Innovation (CMMI) to test a better payment structure for dementia care management. This model would:

- Provide services such as the development of a dementia care plan, care coordination and navigation, and caregiver education and support.
- Ensure patients have access to an interdisciplinary team of providers with dementia care expertise.
- Reimburse providers through a capitated payment and an incentive payment based on performance.



COMPREHENSIVE CARE FOR ALZHEIMER'S ACT BACKGROUND AND TALKING POINTS

ASK Please cosponsor the *Comprehensive Care for Alzheimer's Act*, which would ask the Center for Medicare and Medicaid Innovation (CMMI) to implement a dementia care management model.

BACKGROUND

The Alzheimer's Association and the Alzheimer's Impact Movement (AIM) strongly support the bipartisan Comprehensive Care for Alzheimer's Act (S. 1125/H.R. 2517), which was introduced by Senators Debbie Stabenow (D-MI) and Shelley Moore Capito (R-WV) in the Senate and Representatives Brian Higgins (D-NY-26), Darin LaHood (R-IL-18), Paul Tonko (D-NY-20), and Brett Guthrie (R-KY-2) in the House of Representatives.

MAKING THE CASE FOR THE COMPREHENSIVE CARE FOR ALZHEIMER'S ACT

Caring for an individual with Alzheimer's or other dementias poses unique challenges. In addition to having complex medical needs — the management of which is complicated by cognitive impairment — they have non-medical needs, like supports to remain in their homes and communities, and help making a wide variety of decisions. But because our health care system doesn't pay for the coordinated care this population requires, persons with dementia, their caregivers, and families are forced to navigate a daunting, costly maze.

Currently, Medicare pays health care providers for each individual service they provide, a system known as Fee-for-Service (FFS). This means that there is no incentive for a clinician to coordinate the delivery of care and services. It also rewards providers for billing for many different services, but not for providing quality health outcomes for their patient. However, there are different kinds of payment systems that do address these issues by paying for the value of the care, including better outcomes for beneficiaries.

At the federal level, the Center for Medicare and Medicaid Innovation (CMMI) is tasked with creating and testing innovative models of care delivery and payment to improve outcomes and reduce costs. It has funded dementia care management models in the past, and those models demonstrated that comprehensive, coordinated dementia care can reduce hospitalizations and emergency department visits and delay nursing home placement, thus improving outcomes and reducing total costs.

Despite their success, however, these dementia care management programs will not spread on their own under the current Medicare system due to the significant upfront financial investment that physician practices must make to launch them. Furthermore, Medicare does not provide reimbursement for many of the patient and caregiver services that are key to these programs' success, like caregiver support and community-based service referrals. We need a system that pays for more of the services persons living with dementia and families need, and one that pays clinicians to deliver high-value — not high-volume — care.

WHAT IS A DEMENTIA CARE MANAGEMENT MODEL?

A dementia care management model includes a variety of services that persons living with dementia and caregivers need, like medical care, referrals to community-based organizations, care navigation assistance, and caregiver support, among others. Just as importantly, the model ensures that the delivery of these services is coordinated and seamless — no more struggling through the maze of services and providers.



COMPREHENSIVE CARE FOR ALZHEIMER'S ACT BACKGROUND AND TALKING POINTS

WHAT DOES THE COMPREHENSIVE CARE FOR ALZHEIMER'S ACT DO?

Through the Comprehensive Care for Alzheimer's Act, Congress would ask CMMI to implement a dementia care management model to test the effectiveness of comprehensive care management services. The model is designed to reach as many Medicare beneficiaries as possible, especially individuals from diverse communities and rural and medically underserved areas.

FREQUENTLY ASKED QUESTIONS

During the course of your meetings with members of Congress and their staff, you may encounter some common questions. We have addressed some of these questions below.

Q. Will Medicare providers or beneficiaries be required to participate?

No, participation in this model is voluntary for both providers and beneficiaries.

Q. What is CMMI?

The Center for Medicare and Medicaid Innovation (CMMI), also known as the CMS Innovation Center, falls under the Centers for Medicare & Medicaid Services (CMS). CMMI is charged with testing innovative payment and delivery models that show the potential to maintain or improve the quality of care in Medicare or Medicaid.

Q. What is Medicare FFS?

Medicare Fee-for-Service is the default system of health care payment in which a Medicare provider is paid separately for each individual service delivered. Approximately two thirds of Medicare beneficiaries are part of the Fee-for-Service system.

Q. What does the *National Plan to Address Alzheimer's Disease* say about a dementia care management model?

This legislation is consistent with the *National Plan to Address Alzheimer's Disease*, Strategy 2.E of which calls for exploration of new models of care for people with Alzheimer's disease and

related dementia. Additionally, the Advisory Council on Alzheimer's Research, Care, and Services recommends further development, evaluation, and use of Alzheimer's and dementia care models that align performance measures, the experience of care by persons living with dementia and their caregivers, and payment.

Q. How much would the *Comprehensive Care for Alzheimer's Act* cost?

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 it 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 Impact Movement's Federal Affairs Team at 202.393.7737. Also indicate the interaction at alzimpact.org so a member of the Federal Affairs team can follow-up with that office.

FACTSHEET

MAY 2021

alzimpact.org

ENACT Act

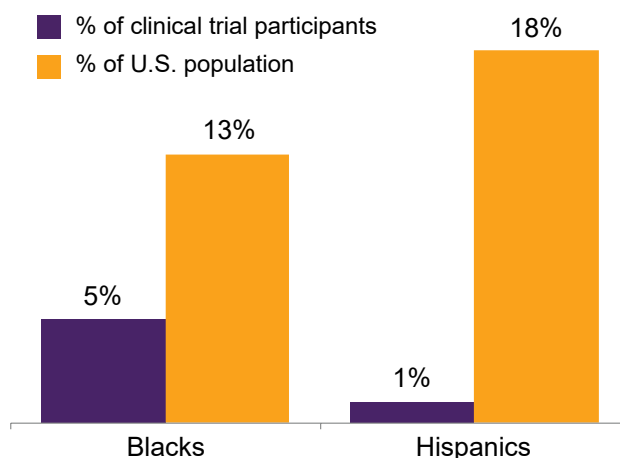
Alzheimer's disease disproportionately affects Black and Hispanic older Americans.

- Although Whites make up the majority of the over 6 million people in the United States with Alzheimer's, research shows that Blacks and Hispanics are at higher risk.
- Blacks are about two times more likely than Whites to have Alzheimer's and other dementias.
- Hispanics are about one and one-half times more likely than Whites to have Alzheimer's and other dementias.

However, Alzheimer's research to date has not included sufficient numbers of Blacks and Hispanics.

- In 2018, across all clinical drug trials (not just Alzheimer's), Blacks represented only 5% of trial participants and Hispanics represented only 1%, despite representing 13% and 18% of the population, respectively.
- The best available evidence suggests that this trend is similar in Alzheimer's research. A study from 2016 found that among 10 recent Alzheimer's biomarker studies, only 2 of them had recruited adequate numbers of Blacks.
- The underrepresentation of racial and ethnic minorities in clinical trials limits knowledge of how a treatment or diagnostic may affect these populations.

Underrepresentation of Blacks and Hispanics in Clinical Trials



Additionally, changing demographics and risk factor profiles necessitate recruitment of more Asian and Native Americans into Alzheimer's clinical trials.

- By 2050 Asian Americans are projected to comprise nearly 8% of those aged 65 and older. However, over the last two decades, less than 1% of the National Institutes of Health's (NIH) total budget has gone to research projects focused on Asian Americans.
- Native Americans have high rates of chronic conditions, including conditions that are suspected risk factors for Alzheimer's, such as obesity, diabetes and hypertension. Despite this, available data suggest that participation of Native Americans in clinical trials is very low.

Including more individuals from traditionally underrepresented populations in Alzheimer's clinical trials will require establishing trust and lowering the burden of participation.

- According to a recent survey, nearly two-thirds of Blacks believe that medical research is biased against people of color. This belief is also held by more than a third of Asian Americans, Hispanics, and Native Americans.
- Additionally, there can be significant barriers for underrepresented populations to access clinical trials. For example, individuals from diverse communities often must travel long distances to research sites, which can result in a substantial financial cost to the participants.

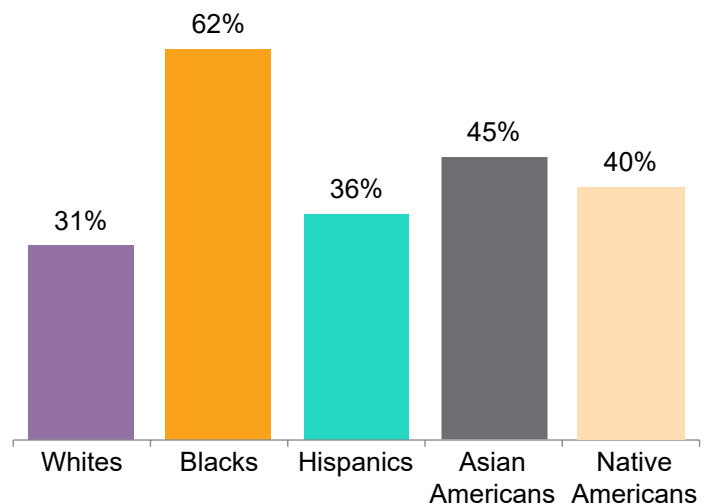
Current NIA Efforts

The National Institute on Aging (NIA) has established centers across the country that offer local resources, support, and opportunities to participate in research on Alzheimer's and other dementias. NIA currently funds 31 Alzheimer's Disease Research Centers (ADRCs) at major medical institutions across the United States and four Exploratory ADRCs that are designed to expand and diversify research and educational opportunities to new areas of the country, populations, areas of science, and approaches to research.

There are also eight Alzheimer's disease-focused Resource Centers for Minority Aging Research (RCMARs). These Centers focus on enhancing the diversity of the aging research workforce through the mentoring of promising scientists from underrepresented groups.

For more information on ADRCs, visit:
nia.nih.gov/research/adc.

Percentage of Adults Who Believe Research is Biased Against People of Color



The Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act (H.R. 3085 / S. 1548) seeks to increase representation in Alzheimer's clinical trials among traditionally underrepresented groups. The bill would:

- Provide funding for the NIA to build trust among underrepresented populations by expanding education and outreach and increasing the diversity of clinical trial staff.
- Reduce the burden associated with participating in clinical trials by:
 - Funding new Alzheimer's Disease Research Centers (ADRCs) and increasing the number of Alzheimer's clinical trials in areas with high concentrations of underrepresented populations.
 - Requiring grant recipients to use community-based engagement strategies in their outreach to underrepresented populations.



EQUITY IN NEUROSCIENCE AND ALZHEIMER'S CLINICAL TRIALS (ENACT) ACT BACKGROUND AND TALKING POINTS

ASK Please cosponsor the *Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act*, which would increase the participation of underrepresented populations in Alzheimer's and other dementia clinical trials.

BACKGROUND

The Alzheimer's Association and the Alzheimer's Impact Movement (AIM) strongly support the bipartisan *Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act* (H.R. 3085 / S. 1548), which was introduced by Senators Ben Ray Lujan (D-NM) and Susan Collins (R-ME) in the Senate and Representatives Lisa Blunt Rochester (D-DE), Jaime Herrera Beutler (R-WA), Chris Smith (R-NJ), John Curtis (R-UT) and Maxine Waters (D-CA) in the House of Representatives. This important legislation would increase the participation of underrepresented populations in Alzheimer's and other dementia clinical trials by expanding education and outreach to these populations, encouraging the diversity of clinical trial staff, and reducing participation burden, among other priorities.

MAKING THE CASE FOR THE ENACT ACT

Alzheimer's and other dementia disproportionately affect older Black and Hispanic Americans compared to older Whites. Black Americans are twice as

likely to develop Alzheimer's and Hispanic Americans are one and a half times more likely to develop the disease. However, much of the Alzheimer's research to date has not included sufficient numbers of Blacks, Hispanics, Asian Americans/ Pacific Islanders and Native Americans to be representative of the U.S. population. The underrepresentation of these populations not only hinders the ability of researchers to understand these health disparities, it also restricts their knowledge of how an approved therapy or diagnostic may affect the population most likely to need the drug. There is therefore an urgent need for current and future research to include increased numbers of Blacks, Hispanics, Asian Americans/ Pacific Islanders, and Native Americans in clinical trials to ensure everyone benefits from advances in Alzheimer's science.

According to the Alzheimer's Association *2021 Alzheimer's Disease Facts and Figures* special report, nearly two-thirds of Black Americans (62%) believe medical research is biased against people of color — a view shared by substantial

numbers of Asian Americans (45%), Native Americans (40%), and Hispanic Americans (36%) as well. In fact, only half of Black Americans (53%) trust a future cure for Alzheimer's will be shared equally regardless of race, color or ethnicity. This underscores the need to build and restore trust in underrepresented communities. Strong community relationships can serve to address misconceptions and mistrust about research because the community has a sense of ownership in the research initiative. Community-based participatory research (CBPR) and engagement with community-based organizations (CBOs) are two strategies that can accomplish this goal.

The National Institute on Aging (NIA) has established a good foundation of centers across the country that offer local resources, support, and opportunities to participate in Alzheimer's and other dementia research. NIA currently funds 31 **Alzheimer's Disease Research Centers (ADRCs)** at major medical institutions across the United States and four Exploratory ADRCs that



EQUITY IN NEUROSCIENCE AND ALZHEIMER'S CLINICAL TRIALS (ENACT) ACT BACKGROUND AND TALKING POINTS

are designed to expand and diversify research and education opportunities to new areas of the country, new populations, and new areas of science and approaches to research. There are also eight Alzheimer's disease-focused **Resource Centers for Minority Aging Research (RCMARs)** which focus on enhancing the diversity of the aging research workforce by mentoring promising scientists from underrepresented groups for sustained careers in aging research. These ADRCs and RCMARs are well-positioned to increase education and outreach activities to underrepresented populations within their communities.

WHAT DOES THE ENACT ACT DO?

The *ENACT* Act would increase the participation of underrepresented populations in Alzheimer's and other dementia clinical trials by expanding education and outreach to these populations, encouraging the diversity of clinical trial staff, and reducing participation burden, among other priorities.

Specifically, the *ENACT* Act would provide funding for NIA to expand the number of ADRCs in areas with higher concentrations of underrepresented populations, such as through entities like Historically Black Colleges

and Universities (HBCUs), Hispanic-Serving Institutions, Tribal Colleges and Universities (TCUs), or centers of excellence for other underrepresented populations. The *ENACT* Act would provide funding for ADRCs and RCMARs to increase education and outreach to underrepresented communities and primary care physicians to let them know about current trial opportunities, the importance of participation, and the disparate impact of the disease on their populations. Importantly, ADRCs and RCMARs would use community-based engagement strategies in their outreach to underrepresented populations.

The *ENACT* Act would direct NIA to enhance the diversity of principal investigators and study staff conducting Alzheimer's and other dementia clinical trials, so they are more representative of the populations they're trying to enroll. The bill directs NIA to provide training to principal investigators from underrepresented populations on topics like clinical protocols and how to apply for grants, so they have the necessary expertise. NIA would also ensure senior researchers from underrepresented populations are included when making awards for leadership and excellence in Alzheimer's research.

The *ENACT* Act would reduce participation burden to make it easier for underrepresented populations to participate in Alzheimer's and other dementia clinical trials by providing incentives for locating Alzheimer's clinical trial sites in areas with high concentrations of underrepresented populations, as identified by data from the U.S. Census and Medicare claims data. The bill would direct NIA to ensure grantees use community-based engagement strategies in their outreach to underrepresented populations. The bill also encourages the use of remote health technology in communities, such as remote patient monitoring, to ease the burden of participation. Importantly, the bill would direct NIA to ensure grantees appropriately budget for outreach activities to underrepresented populations and include a description of outreach plans. NIA would also encourage grantees to engage with community-based organizations in efforts to increase clinical trial participation of underrepresented populations. Finally, the *ENACT* Act authorizes \$60 million per year for five years, from FY22-FY26. The bill leaves flexibility to NIA on how best to use those funds for the legislation's various activities.



EQUITY IN NEUROSCIENCE AND ALZHEIMER'S CLINICAL TRIALS (ENACT) ACT BACKGROUND AND TALKING POINTS

FREQUENTLY ASKED QUESTIONS

During the course of your meetings with members of Congress and their staff, you may encounter some common questions. We have addressed some of these questions below.

What actions has NIA taken to increase the participation of underrepresented populations in Alzheimer's and other dementia clinical trials?

- » NIA, with facilitation by the Alzheimer's Association, released a **"National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research"** which outlines practical, proactive approaches to help study sites and researchers recruit and retain adequate numbers of diverse volunteers for a growing number of studies in Alzheimer's and other dementia. The recommendations focus on increasing awareness and engagement, building and improving research infrastructure, engaging local communities and support participants, and developing an applied science of recruitment.
- » NIA has also released the **"Alzheimer's Disease and Related Dementias Clinical Studies Recruitment Planning Guide"** focused on the recruitment and retention of diverse participants in Alzheimer's and other dementia clinical trials, including strategies to develop equitable and sustainable community partnerships founded on trust; promote health and science literacy for healthcare providers, community partners, patients, and families; and implement system reforms and infrastructure to address bias in workforce diversity and cultivation of community bridges to increase capacity for inclusive outreach.
- » Additionally, NIA has created **Alzheimer's & Dementia Outreach, Recruitment & Engagement Resources (ADORE)**, a repository of resources to support the recruitment and retention of participants into clinical trials and studies.
- » More broadly, NIA created the **NIA Health Disparities Research Framework** which highlights priorities and investments in this important aging research area, designed to serve as a resource for scientists interested in investigating health disparities related to aging.
- » These helpful resources have laid the groundwork for efforts to increase the diversity of participants in Alzheimer's clinical trials. The *ENACT* Act would build upon this foundation and apply these strategies nationwide to expand efforts to increase the participation of underrepresented populations in Alzheimer's and other dementia clinical trials.



EQUITY IN NEUROSCIENCE AND ALZHEIMER'S CLINICAL TRIALS (ENACT) ACT BACKGROUND AND TALKING POINTS

Q. What actions has the Alzheimer's Association taken to increase the participation of underrepresented populations in Alzheimer's and other dementia clinical trials?

- » The Alzheimer's Association has made increasing the participation of underrepresented populations in clinical trials a priority in our research and engagement efforts, including offering targeted programs to expand the diversity and inclusiveness of scientists in Alzheimer's and other dementia research and including language in our grant agreements for all awardees regarding the expectations of diverse and inclusive recruitment for all clinical studies.
- » One specific example of our work to diversify trial participants is the U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER).

» U.S. POINTER sites were selected based, in part, on their history of engagement and reach into their communities. The Alzheimer's Association considered factors of the community networks from both the clinical (health system and academic partners) and Association teams, and we have made it a priority to develop a grassroots strategy for community-based engagement and recruitment within the site community. This builds upon the networks linking community-based organizations, community leaders, and the clinical research teams.

- » So far, U.S. POINTER sites have been successful in enrolling over 25% of participants from underrepresented populations, which is in line with the overall population in those communities.
- » In addition, the *New IDEAS Study* aims to be among the most racially and ethnically diverse Alzheimer's studies ever launched. At least 4,000 of the planned 7,000 *New IDEAS* participants will be Black/African American and Hispanic/Latino, populations historically underrepresented in dementia research.

» Finally, while recruitment is a crucial focus, it is also important to continue to engage participants throughout the trial process to ensure retention. The Alzheimer's Association and AIM support retention efforts like engaging participants through a communication portal, providing enrollees with information and resources throughout the trial, and establishing participant support groups.

Q. What is community-based engagement?

- » Community-based engagement is a collaborative research approach that is designed to ensure participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being.
- » Examples of community-based engagement include community presentations, media outreach, community advisory boards, and flagship events.



EQUITY IN NEUROSCIENCE AND ALZHEIMER'S CLINICAL TRIALS (ENACT) ACT BACKGROUND AND TALKING POINTS

Q. Is the *ENACT* Act consistent with the *National Plan to Address Alzheimer's Disease*?

- » Yes, the *ENACT* Act is consistent with the goals in the *National Plan to Address Alzheimer's Disease* which includes Action 1.B.4, "Monitor and identify strategies to increase enrollment of racial and ethnic minorities in Alzheimer's disease and related dementias studies."



Q. Should we be asking Appropriators to support the \$60 million per year authorized in the *ENACT* Act?

- » No. While the *ENACT* Act authorizes \$60 million per year for five years, the bill first has to be signed into law before we can request that funding through the appropriations process.
- » This is very similar to the *BOLD Infrastructure for Alzheimer's Act*, which authorized \$20 million per year. We advocated for *BOLD*'s passage in 2018 and once enacted, we then began advocating for that funding through the appropriations process in 2019.

Q. Will the *ENACT* Act slow down research efforts or cause clinical trials to take longer?

- » No. The *ENACT* Act provides additional resources to ensure researchers running clinical trials are able to supplement current and future enrollment efforts.
- » This increased funding ensures they do not have to divert any resources away from the important research being done.
- » The *ENACT* Act also would strengthen awareness of and access to clinical trials, as well as build trust within communities, which will help researchers with recruitment.
- » Additionally, there is nothing in the bill that prevents clinical trials from moving forward at the pace they do now.

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Fiscal Year 2022 Alzheimer's Research Funding

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

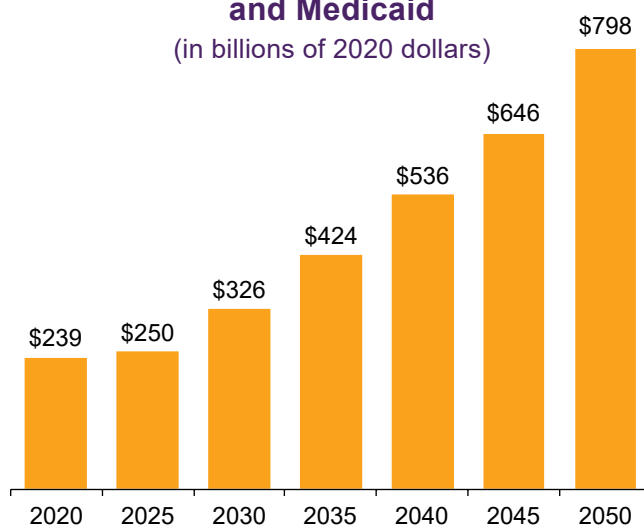
- Alzheimer's is one of the most expensive diseases in America, costing more than heart disease and cancer.
- In 2021, caring for people with Alzheimer's and other dementias will cost the United States an estimated \$355 billion. Cumulatively between 2021 and 2050, it will cost \$20 trillion (in 2021 dollars) — 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 2021, Congress provided an additional \$300 million in Alzheimer's research funding at the National Institutes of Health (NIH).
- With this increase, along with previous research investments, NIH spending on Alzheimer's research is expected to total \$3.1 billion in 2021.
- However, this is still short of the total funding scientists and the federal Alzheimer's Advisory Council have indicated is necessary for continued progress.

Alzheimer's Costs to Medicare and Medicaid

(in billions of 2020 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.
- To help achieve this, the NIH Alzheimer's bypass budget — what the NIH scientists say they need — calls for an additional \$289 million in Alzheimer's research funding for fiscal year 2022.
- This increase will allow the NIH to accelerate investment in collaborations that speed discovery, ground breaking prevention trials, and the testing of new therapeutics.



INCREASE THE COMMITMENT TO ALZHEIMER'S RESEARCH FUNDING BACKGROUND AND TALKING POINTS

ASK Please ask the Chair and Ranking Member of the House/Senate Appropriations Committee to support an additional \$289 million in Fiscal Year 2022 (FY22) for Alzheimer's research activities at the National Institutes of Health (NIH).

BACKGROUND

In December 2020, Congress appropriated a \$300 million increase for Alzheimer's research funding in FY21, bringing the annual allocation to over \$3.1 billion. This significant increase builds upon several years of historic funding increases and is an important investment in research. These funding increases have enabled significant advances in understanding the complexities of Alzheimer's and have been critical to progress toward the primary research goal to effectively treat and prevent Alzheimer's by 2025. This research investment has led to the Food and Drug Administration (FDA) approval of PET scans to identify two biomarkers that help clarify an Alzheimer's diagnosis and FDA is currently reviewing an application for cerebrospinal fluid. Biomarkers are essential for identifying early signs of the disease, before an individual has cognitive damage from dementia, and for developing effective ways to prevent and treat the disease. A simple blood test for Alzheimer's is also closer than ever before — breakthrough research has found that specific markers in the blood may be able to detect changes in the brain 20 years before Alzheimer's symptoms occur. In addition to these great advances, there is a drug under

review at FDA, for the first time, that may treat the underlying biology of the disease.

However, even with this great progress, there is still much left to be done. Investment in Alzheimer's research is still only a fraction of what's been applied over time to address other major diseases. It is vitally important that NIH continues to build upon these, and many other, promising research advances. Increased funding would enable scientists to conduct more inclusive, efficient, and practical clinical trials; increase knowledge of risk and protective factors in individuals and across diverse populations; discover better biomarkers to detect disease and monitor treatment response; pursue a precision medicine approach to detect the disease earlier and tailor treatment plans to an individual's unique symptoms and risk profile; and leverage emerging digital technologies and big data to speed discoveries. Congress must continue its commitment to the fight against Alzheimer's by increasing funding for Alzheimer's research at NIH by an additional \$289 million in FY22.

MAKING THE CASE FOR RESEARCH FUNDING

- * As the current pandemic has shown, continued investment in medical research is absolutely critical to understanding and responding to diseases.
- * Recent funding increases for Alzheimer's research have led to significant scientific progress toward understanding what causes the disease, as well as developing interventions that may prevent and treat it.
- * This investment has helped diversify the research pipeline and has been crucial to expanding additional targets beyond beta-amyloid, resulting in more shots on goal.
- * However, much work remains to be done for the progress this disease requires.
- * Continued and sustained investment is needed to develop a better understanding of how and why Alzheimer's affects diverse communities in different ways; increase knowledge of risk and protective factors in individuals across all populations; and discover better biomarkers to detect the disease and monitor treatment response, among many other important research priorities.



INCREASE THE COMMITMENT TO ALZHEIMER'S RESEARCH FUNDING BACKGROUND AND TALKING POINTS

- * Caring for individuals with Alzheimer's disease cost \$305 billion in 2020, with Medicare and Medicaid bearing \$206 billion — 68 percent — of that figure.
- * By mid-century, the number of people with the disease is set to nearly triple, and the costs of Alzheimer's disease are projected to more than quadruple to \$1.1 trillion (not adjusted for inflation).
- * However, estimates suggest that if a treatment became available in 2025 that delayed the onset of Alzheimer's for five years, Medicare and Medicaid would save a cumulative \$535 billion over just the first ten years after that treatment became available.
- * Congress must continue its commitment to the fight against Alzheimer's by increasing funding for Alzheimer's research by an additional \$289 million in FY22.

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.

FREQUENTLY ASKED QUESTIONS

During the course of your meetings with members of Congress and their staff, you may encounter some common questions. We have addressed some of these questions below.

Q. Congress has recently passed massive spending bills to address COVID-19; how does that affect this request for a \$289 million increase?

- » While Congress has taken steps to respond to the COVID-19 pandemic through recent spending bills, the FY22 appropriations process continues to move forward.
- » Increased funding for Alzheimer's research at NIH needs to be included in those FY22 appropriations bills.
- » As the number of people living with Alzheimer's continues to grow, and as Medicaid and Medicare spending on Alzheimer's escalates, it is increasingly important to invest in treatments that will help improve care.

Q. Will NIH be able to use the requested increased funding to conduct Alzheimer's research and fund related grants during the COVID-19 pandemic?

- » Yes. While COVID-19 temporarily slowed some aspects of research, many studies continue on modified schedules or through virtual engagement. Researchers are staying in contact with participants through phone calls, video conferences, internet contacts, and through the mail.
- » Clinics are also back and running for most centers and while research labs may be at reduced capacity, they are continuing to move forward and conduct studies.
- » NIH has also offered supplemental funding opportunities to support researchers through this time and to accelerate research impacted by COVID-19 delays.
- » As COVID-19 significantly impacts the Alzheimer's community, it is important that we continue to push research forward to best support and treat individuals in the aging population safely and effectively.



INCREASE THE COMMITMENT TO ALZHEIMER'S RESEARCH FUNDING BACKGROUND AND TALKING POINTS

Q. How does COVID-19 affect Alzheimer's and other dementia?

- » There is a link between COVID-19 and brain dysfunction. Many people have reported loss of smell and taste, and "brain fog."
- » However, more research is needed to better understand this link. The inflammation response and breakdown of the blood brain barrier found in those with COVID-19 are also important biologies that are found in people with Alzheimer's and other dementia.
- » Increased investment in Alzheimer's research is needed to better understand what these links may be and how the virus may affect the brain, memory, and behavior in people at different ages and from different genetic backgrounds.



Q. How does this request relate to the National Alzheimer's Project Act (NAPA)?

- » 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 Plan to Address Alzheimer's Disease, 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.
- » The primary research goal of the National Plan to Address Alzheimer's Disease is to effectively treat or prevent Alzheimer's by 2025.
- » The requested \$289 million increase is what NIH scientists and others in the field agree is needed to help reach that 2025 goal.

Q. NIH already receives funding for Alzheimer's; why the additional \$289 million?

- » 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 or preventing Alzheimer's by 2025.
- » The "Milestones" leave-behind highlights some of the important research advances made with these funding increases, such as identifying new biomarkers to detect the disease and a better understanding of how genetic risk factors differ in diverse populations.
- » However, even with this great progress, investment in Alzheimer's research is still 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.



INCREASE THE COMMITMENT TO ALZHEIMER'S RESEARCH FUNDING BACKGROUND AND TALKING POINTS

Q. The FY22 Bypass Budget requests an additional \$289 million for Alzheimer's research at the NIH for a total of \$3.1 million. If we already have \$3.1 billion, why advocate for a \$289 million increase?

- » The Alzheimer's Bypass Budget, released annually by the NIH, specifies the resources scientists need to fulfill the primary research goal of the National Plan and the U.S. Alzheimer's Advisory Council.
- » An additional \$289 million would allow the NIH to accelerate investment in collaborations that speed discovery, groundbreaking prevention trials, the testing of new therapeutics, and many other opportunities.
- » The Alzheimer's Association's medical science team agrees that these requested funds can support meritorious Alzheimer's research proposals.

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

- » 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.
- » 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 initiatives to address biomedical research funding, like the 21st Century Cures Act, impact funding for Alzheimer's research?

- » The Alzheimer's Association strongly supported the 21st Century Cures Act (P.L. 114-255). 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 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 Impact Movement's Federal Affairs Team at 202.393.7737. Also indicate the interaction at alzimpact.org so a member of the Federal Affairs team can follow-up with that office.

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BOLD Infrastructure for Alzheimer's Act

Alzheimer's and other dementias are an urgent public health issue.

- More than 6 million Americans have Alzheimer's.
- It is one of the most expensive diseases in America; costs will total \$355 billion in 2021.
- And the burden is growing larger. The number of people living with Alzheimer's is projected to more than double to 12.8 million in 2050, and the costs are expected to rise to more than \$1.1 trillion.

There are several ways that the public health community can address the crisis.

- **Primary Prevention:** A growing scientific consensus has concluded that healthy living can reduce the risk of cognitive decline and may reduce the risk of Alzheimer's. Public health can integrate brain health messages into existing, relevant public health campaigns.
- **Early Detection and Diagnosis:** As many as half of people living with Alzheimer's have not been diagnosed. Public health can undertake public awareness campaigns to promote early detection and diagnosis and can educate medical professionals about assessment tools.
- **Data Collection:** States can collect data on cognitive decline and Alzheimer's caregiving using tools such as the Behavioral Risk Factor Surveillance System (BRFSS).
- **Access to Care and Services:** Public health can encourage health professionals to follow evidence-based clinical care guidelines, create tools to aid in the delivery of care, and report on quality care dementia practices.

The BOLD Infrastructure for Alzheimer's Act (P.L. 115-406) establishes a public health infrastructure to address dementia.

- In 2018, the bipartisan BOLD Act was unanimously approved by the Senate and passed in the House of Representatives by a vote of 361-3.
- With initial congressional funding, the CDC is:
 - Funding three Alzheimer's Centers of Excellence to expand and promote innovative and effective Alzheimer's interventions.
 - Providing grants to 16 state, local, and tribal public health departments to implement interventions, including those in the *Public Health Road Map*.
 - Increasing the analysis and timely reporting of data on cognitive decline and caregiving to inform future public health actions.

Congress must continue its commitment to addressing this public health crisis by fully funding the BOLD Act.

- The BOLD Act authorized \$100 million over five years to carry out various public health activities addressing Alzheimer's and other dementias.
- For fiscal year 2021, Congress provided \$15 million to implement the BOLD Act. Now, Congress must fully fund the law by providing \$20 million in fiscal year 2022 for the CDC.
- Fully funding the BOLD Act will enable CDC to award additional Centers of Excellence, focus on important priorities such as Tribal Health, and expand the number of state, local, and tribal public health departments that receive grants.



INCREASE THE COMMITMENT TO ALZHEIMER'S PUBLIC HEALTH RESPONSE BACKGROUND AND TALKING POINTS

ASK Please ask the Chair and Ranking Member of the House/Senate Appropriations Committee to support the full \$20 million in Fiscal Year 2022 (FY22) for implementation of the BOLD Infrastructure for Alzheimer's Act at the Centers for Disease Control and Prevention (CDC).

BACKGROUND

Now more than ever it is apparent how crucial it is to have an established infrastructure in place to respond to public health threats. Public health plays an important role in promoting brain health and reducing the risk of cognitive decline. Investing in a nationwide Alzheimer's public health response will achieve a higher quality of life for those living with the disease and their caregivers, and reduce associated costs.

The bipartisan Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L. 115-406) was unanimously approved in the Senate, passed by a vote of 361-3 in the House of Representatives, and signed into law on December 31, 2018. The law directs the Centers for Disease Control and Prevention (CDC) to strengthen the public health infrastructure across the country by implementing effective Alzheimer's interventions focused on public health issues such as increasing early detection and diagnosis, reducing risk, meeting the needs of caregivers and addressing social determinants of health.

BOLD authorized \$20 million each year for five years (Fiscal Years 2020-2024). Congress appropriated \$10 million for the first year of BOLD's implementation in FY20, which

allowed CDC to award funding to three Public Health Centers of Excellence and 16 public health departments across the country. Importantly, one of those Centers of Excellence is focused entirely on risk reduction, and the Alzheimer's Association is grateful for the opportunity to lead this center. Congress appropriated \$15 million for the second year of BOLD's implementation in FY21 which will help fund additional public health departments. While these are meaningful steps forward, Congress must appropriate the full \$20 million authorized in the law for FY22 in order to adequately address Alzheimer's as a public health threat.

MAKING THE CASE FOR RESEARCH FUNDING

- * As the current pandemic has shown, it is crucial to have an established infrastructure in place to respond to public health threats.
- * Alzheimer's is a public health threat because it affects so many people around the country — more than 6 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.

- * Over half of Congress cosponsored the authorizing law, so it is clear there is strong bipartisan support for BOLD in both the House and Senate.
- * The intent of BOLD is to establish Alzheimer's and Related Dementias Public Health Centers of Excellence; provide funding to state, local, and tribal public health departments; and increase data analysis and timely reporting.
- * This important public health infrastructure will implement effective Alzheimer's interventions focused on public health issues such as increasing early detection and diagnosis, reducing risk, meeting the needs of caregivers, and addressing social determinants of health.
- * Congress appropriated \$10 million for the first year of BOLD's implementation in FY20, which allowed CDC to award funding to three Public Health Centers of Excellence and 16 public health departments across the country.
- * Congress appropriated \$15 million for the second year of BOLD's implementation in FY21, which will help fund additional public health departments across the country.



INCREASE THE COMMITMENT TO ALZHEIMER'S PUBLIC HEALTH RESPONSE BACKGROUND AND TALKING POINTS

* The next step in BOLD's implementation is for Congress to fully fund the \$20 million authorized in the law for CDC in FY22.

* This crucial funding will enable CDC to award additional Public Health Centers of Excellence, focused on important priorities like Tribal Health, and expand the number of state, local and tribal public health departments that receive funding for Alzheimer's public health activities.

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.

FREQUENTLY ASKED QUESTIONS

During the course of your meetings with members of Congress and their staff, you may encounter some common questions. We have addressed some of these questions below.

Q. Congress appropriated \$15 million for BOLD in FY21; does that mean this \$20 million request is an increase for a total of \$35 million?

- » No, this request is for the full \$20 million authorized in the law for BOLD's implementation at CDC in FY22.
- » The law authorized \$20 million for each fiscal year from FY20-24 so Congress will have to appropriate those funds each year.
- » The \$15 million Congress appropriated in FY21 is in the process of being allocated and the request for \$20 million in FY22 is separate.

Q. What awards has CDC made with the funding Congress has appropriated for BOLD so far?

- » Using FY20 funding, CDC awarded funding to three Public Health Centers of Excellence (PHCOE): the Alzheimer's Association is leading a Center on Risk Reduction, the University of Minnesota is leading a Center on Caregiving and New York University is leading a Center on Dementia Risk Reduction.
- » Using FY20 funding, CDC also awarded funding to 16 public health departments across the country: Colorado, Hawaii, Iowa, Los Angeles County, Maine, Mississippi, Nevada, North Carolina, Northwest Portland Area Indian Health Board, Oklahoma, Vermont, Georgia, Minnesota, Rhode Island, Virginia and Wisconsin.
- » The \$15 million CDC just received for FY21 is in the process of being allocated. That funding will go toward continuation of existing award activities, as well as an expansion of the number of state, local and tribal public health departments that receive funding for Alzheimer's public health activities.



INCREASE THE COMMITMENT TO ALZHEIMER'S PUBLIC HEALTH RESPONSE BACKGROUND AND TALKING POINTS

Q. How much of the requested \$20 million will go toward Public Health Centers of Excellence, versus public health departments or data analysis and timely reporting?

- » Receiving the full \$20 million in FY22 will enable CDC to award additional Public Health Centers of Excellence, focused on important priorities like Tribal Health, and expand the number of state, local and tribal public health departments that receive funding for Alzheimer's public health activities.
- » However, the final BOLD legislative language did not specify how much of the funding will go toward the different activities authorized in the law.
- » CDC will ultimately determine how the \$20 million breaks down between the Public Health Centers of Excellence, public health departments, or data analysis and timely reporting.

Q. Will CDC make awards to increase data analysis and timely reporting?

- » CDC has the option on whether or not to issue funding for data analysis and timely reporting because Congress gave that flexibility to CDC.
- » CDC has not yet issued a notice of funding opportunity for this section of BOLD. Instead it has used the flexibility Congress provided and prioritized PHCOEs and cooperative agreements to State, local and tribal health departments.

Q. Is the funding in BOLD the same as funding for the Healthy Brain Initiative?

- » No, the funding authorized by BOLD is separate from the funds already appropriated for the Healthy Brain Initiative (HBI).
- » The Alzheimer's Association and AIM are requesting \$17 million for HBI funding and \$20 million for BOLD funding in FY22.

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 Impact Movement's Federal Affairs Team at 202.393.7737. Also indicate the interaction at alzimpact.org so a member of the Federal Affairs team can follow-up with that office.

FACTSHEET

MARCH 2021

alzimpact.org

Alzheimer's Caregiver Support Act

Alzheimer's disease has a devastating impact not just on those with the disease. It's also a burden on their caregivers — a job that usually falls on family and friends.

- Nearly half of all caregivers who provide help to older adults do so for someone with Alzheimer's or another dementia.
- In 2020, family members and friends of individuals living with dementia provided unpaid care valued at nearly \$257 billion.
- On average, each dementia caregiver today spends 20% more time providing care than a dementia caregiver did a decade ago. This is the equivalent of nearly six more full work weeks of unpaid care each year.

Alzheimer's and dementia caregivers often provide care that is more extensive and intimate than that of other caregivers.

- Nearly 80% of older adults with dementia receive help with a daily personal care activity such as bathing, dressing, grooming, or eating. In contrast, only 20% of older adults without dementia need help with these activities.
- One in 3 Alzheimer's caregivers provide help bathing or showering, feeding, or getting to and from the toilet — a higher percentage than caregivers of other older adults.
- Nearly two-thirds of dementia caregivers expect to continue to provide care for the next five years, compared with less than half of other caregivers.

Although caregiving is often rewarding, the intense responsibilities often take a toll on the caregiver.

- More than half of dementia caregivers report having no experience performing medical or nursing related tasks. In addition, dementia caregivers are twice as likely as other caregivers to report that these tasks are difficult.
- Nearly 75% of Alzheimer's and dementia caregivers are concerned about maintaining their own health since becoming a caregiver.
- More than 1 in 3 dementia caregivers say their health has gotten worse due to their care responsibilities. More than a quarter of dementia caregivers delay or do not do things they should to maintain their own health.

The Alzheimer's Caregiver Support Act (S. 56 / H.R. 1474) would help provide critical training and relief to Alzheimer's and dementia caregivers.

- The bill would provide grants for training and support services for families and unpaid caregivers of individuals living with Alzheimer's disease or another dementia.
- Those eligible to receive grants include community health centers, senior centers, and state agencies.
- At least 10% of the funding must go to those who serve caregivers in medically underserved communities.



ALZHEIMER'S CAREGIVER SUPPORT ACT BACKGROUND AND TALKING POINTS

ASK Please cosponsor the *Alzheimer's Caregiver Support Act (S. 56/ H.R. 1474)*, which would provide grants to organizations to expand training and support services for families and unpaid caregivers of individuals living with Alzheimer's disease and related dementia.

BACKGROUND

The Alzheimer's Association and the Alzheimer's Impact Movement (AIM) strongly support the bipartisan *Alzheimer's Caregiver Support Act (S. 56/ H.R. 1474)*, which was introduced by Senators Amy Klobuchar (D-MN) and Susan Collins (R-ME) in the Senate and Representatives Maxine Waters (D-CA-43) and Chris Smith (R-NJ-4) in the House. This legislation would authorize grants to organizations to expand training and support services for families and unpaid caregivers of those living with Alzheimer's disease and other dementia.

MAKING THE CASE FOR THE ALZHEIMER'S CAREGIVER SUPPORT ACT (S. 56 / H.R. 1474)

Nearly half of all caregivers who provide help to older adults do so for someone with Alzheimer's or another dementia. In 2020, more than 11 million caregivers of people with Alzheimer's or other dementias provided an estimated 15.3 billion hours of unpaid care, a contribution to the nation valued at \$257 billion.

More than half of all dementia caregivers have at least one chronic condition of their own, and nearly a quarter suffer from depression. On average, each

dementia caregiver today spends 20 percent more time providing care than a dementia caregiver did 10 years ago. Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers, meaning that they care not only for an aging parent, but also for children under age 18. Many family caregivers of persons with dementia have to quit their jobs, reduce their work hours, or take time off because of caregiver responsibilities.

TYPES OF ACTIVITIES UNDERTAKEN BY CAREGIVERS

Though the care provided by family members of people with Alzheimer's or other dementias is somewhat similar to the help provided by caregivers of people with other conditions, dementia caregivers tend to provide more extensive assistance.

- * Family caregivers of persons with dementia are more likely to monitor the health of people living with dementia than are caregivers of people without dementia (79 percent versus 66 percent).
- * Family caregivers of persons with dementia are more likely than caregivers of people without dementia to provide help with self-care and mobility (85 percent versus 71 percent) and health or medical care (63 percent versus 52 percent).

- * 77 percent of older adults with dementia receive informal assistance with at least one activity of daily living or household activity in contrast to only 20 percent of older adults without dementia.

These caregivers are also more likely to advocate for these individuals with community agencies and care providers, manage finances, and arrange for outside services. They manage a person's neuropsychiatric symptoms, the loss of memory and judgment, co-morbidities, and the impact of the disease on the family.

HEALTH OF CAREGIVERS FOR PERSONS LIVING WITH DEMENTIA

Caregivers are often physically and mentally exhausted after caring for a loved one. Though often rewarding, these extensive and intensive responsibilities over multiple years often take a toll on caregivers of persons living with dementia. Twice as many caregivers of those with dementia indicate substantial financial, emotional, and physical difficulties compared with caregivers of people without dementia. The prevalence of depression among dementia caregivers is higher than other caregivers, and the risk for depression increases as the cognitive impairment worsens in the person with dementia.



ALZHEIMER'S CAREGIVER SUPPORT ACT BACKGROUND AND TALKING POINTS

Their physical health also suffers: 42 percent of caregivers of people with Alzheimer's or another dementia report that their health is excellent or very good, which is lower than caregivers of people without dementia (50 percent). Dementia caregivers indicated lower health-related quality of life than non-caregivers and they are more likely than non-caregivers or other caregivers to report that their health is fair or poor. The physical and emotional impact of dementia caregiving is estimated to have resulted in \$11.8 billion in health care costs in the United States in 2018.

The unique challenges and needs of dementia caregiving and the impact of dementia requires comprehensive and robust action for this large and growing number of caregivers. The more caregivers understand Alzheimer's disease or other dementia, the better they can care for their loved ones and themselves.

WHAT DOES THE ALZHEIMER'S CAREGIVER SUPPORT ACT DO?

This bill would authorize grants to public and non-profit organizations to expand training and support services for families and unpaid caregivers of people living with Alzheimer's disease and other dementia.

These services can improve caregivers' health and allow those living with a diagnosis to stay in their homes longer. Eligible grant recipients would include health care organizations, community health centers, senior centers, Area Agencies on Aging, community-based organizations, organizations providing support services for families and unpaid caregivers, social service agencies, and state, local, and tribal health agencies.

The bill would ensure that grantees provide public outreach on the services they offer under this program. The Secretary of Health and Human Services would need to coordinate with the Directors of the Office of Minority Health and the Office of Women's Health to ensure that women, underrepresented populations, and medically underserved communities benefit from this program.

The bill would authorize the necessary appropriations for each of the fiscal years 2021 through 2025 and would direct at least 10 percent of those funds to applicants that primarily service medically underserved communities.

HOW DOES THIS LEGISLATION ADDRESS ISSUES WITHIN THE NATIONAL PLAN TO ADDRESS ALZHEIMER'S DISEASE?

The important provisions of this legislation are consistent with the National Plan to Address Alzheimer's Disease which calls for enhancing public outreach about Alzheimer's disease resources and services. Additionally, caregiving appears throughout the National Plan to Address Alzheimer's Disease, and under each of the five goals, from research on effective caregiving interventions to caregiver education. Goal 3, "Expand Supports for People with Alzheimer's Disease and Related Dementias and Their Families," focuses specifically on caregivers, ensuring that they receive culturally-sensitive training and support, as well as their own health and well-being as they support persons living with dementia.

SHARE YOUR STORY

Tell your personal story. If you are comfortable doing so, please share your experience with the economic pressures created by caring for a loved one living with Alzheimer's or other dementia.



ALZHEIMER'S CAREGIVER SUPPORT ACT BACKGROUND AND TALKING POINTS

FREQUENTLY ASKED QUESTIONS

During the course of your meetings with members of Congress and their staff, you may encounter some common questions. We have addressed some of these questions below.

Q. Who is eligible to receive the grants under this legislation?

Eligible grant recipients would include:

- » health care organizations
- » community health centers
- » senior centers
- » Area Agencies on Aging
- » community-based organizations
- » organizations providing support services for families and unpaid caregivers
- » social service agencies
- » state, local, and tribal health agencies

Q. What types of programs and services would these grants cover?

These grants would cover a variety of training and services including caregiver support groups, group education, and skills-training sessions. Group education and skills-training programs focus on enhancing caregiver knowledge, coping with stress, care planning, problem solving, managing

behavioral symptoms, encouraging persons living with dementia to participate in daily tasks and activities, and understanding the injury or illness of persons needing care.

Q. What is the cost of this legislation?

The Alzheimer's Association and AIM will work with bill sponsors and appropriators during the appropriations process to determine what level of funding will have a meaningful impact on this program. Additionally, the bill has not been scored by the Congressional Budget Office (CBO), however, the Association and AIM will continue to work with the bill sponsors to determine the impact it would have on federal spending.

Q. Why are the House and Senate Bills different?

At the beginning of a new Congress, members of Congress reintroduce legislation from previous years. The Senate bill was introduced early in the new Congress. Since the House version had not yet been reintroduced, the Alzheimer's Impact Movement worked with the House sponsors to clarify the bill language and intent prior to reintroduction. While the differences between the House and Senate versions are small, the Association and AIM will work with both sides to reconcile the language as the bill moves through the legislative process.

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 Impact Movement's Federal Affairs Team at 202.393.7737. Also indicate the interaction at alzimpact.org so a member of the Federal Affairs team can follow-up with that office.



2021 PUBLIC HEALTH PRIORITIES

Mitigating the future impacts of Alzheimer's and other dementias requires state and local governmental public health agencies to robustly promote risk reduction of cognitive decline, improve care for people living with cognitive impairment, and strengthen support for caregivers as recommended in the Healthy Brain Initiative's *State and Local Public Health Partnerships to Address Dementia: The 2018–2023 Road Map*.

1

INCREASE EARLY DIAGNOSIS OF ALZHEIMER'S

Only about 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 the diagnosis — are essential to enhancing medical care for people living with dementia. Diagnoses also enable all affected to access information, services, and other support in the community and make plans for the future. State and local governmental public health agencies must ensure health care professionals have the competencies needed to effectively discuss memory issues and use validated cognitive assessment tools. Agencies also must directly educate the public about cognitive changes that should be discussed with a provider as well as the benefits of early diagnosis. State health improvement plans should include goals regarding early diagnoses.

2

PROMOTE RISK REDUCTION OF COGNITIVE DECLINE

Healthy behaviors — which research has shown to prevent cancer, diabetes, and cardiovascular disease — also may reduce risk for cognitive decline and possibly dementia. With budget allocations from state legislatures, governmental public health agencies must advance awareness about the interplay between cognitive health and physical health through culturally competent health education campaigns, especially for diverse communities. Public health agencies can also improve access to interventions and services that support cognitive and heart health and establish policies that ensure people living with dementia and their caregivers have safe, supportive communities with opportunities to stay engaged and live as independently as possible.

3

INCREASE ATTENTION TO DEMENTIA CAREGIVERS

The challenges of caring for persons living with Alzheimer's and other dementias can become difficult and overwhelming, especially when intensive care is needed for long periods of time. State and local governmental public health agencies can ensure equitable access to needed services and supports for caregivers of people living with dementia, minimize fragmentation and inadequate coordination, and better meet the needs of diverse populations. Public health agencies and their partners also can ensure attention to caregiving occurs across the full community so caregivers can continue providing vital, effective care in ways that protect both their health and the health of people living with dementia.

4

BUILD A DEMENTIA- CAPABLE WORKFORCE

As the nation ages, more people will develop Alzheimer's and other dementias and need high quality, compassionate care. State and local governmental public health agencies must strengthen competencies of professionals, especially physicians and primary care clinicians, who deliver health care and other care services to people living with dementia. Agencies can also assure academic programs, professional associations, and accreditation and certification entities incorporate the best available science into training for the health care and public health workforces. Finally, these agencies also can evaluate professional dementia training and caregiving support programs to identify ways to improve impact.

5

ENHANCE NATIONWIDE, STATE, AND LOCAL SURVEILLANCE

Surveillance is a fundamental and essential public health tool to understanding the prevalence of disease, health risk factors, preventive health behaviors and burden. State and local governmental public health agencies can enhance data collection and timely analysis of cognitive health issues, workforce capacities, and dementia caregiving. Two specific priorities are implementing the Cognitive Decline and Caregiver Modules of the Behavioral Risk Factor Surveillance System (BRFSS) and estimating the gap between workforce capacity and anticipated demand for services to support people living with dementia and their caregivers.



2021 STATE POLICY PRIORITIES

Alzheimer's is a growing public health crisis and state governments must take bold action.

Effectively implementing and updating State Alzheimer's Plans and supporting other policies will reduce the long-term impact of the disease on state budgets, and improve the lives of individuals living with dementia and their family caregivers.

1

INCREASE PUBLIC AWARENESS, EARLY DETECTION AND DIAGNOSIS

Most people who have been diagnosed with Alzheimer's disease are not aware of their diagnosis, and only about half of those with Alzheimer's have been diagnosed. Diagnosis — and disclosure of that diagnosis — is necessary for care planning, which is critical to improving outcomes for the individual. State officials must work to educate health care providers and the public about the importance of early detection and diagnosis, and improve access to and awareness of resources such as the Medicare Annual Wellness visit. Through public health campaigns and data collection via the Behavioral Risk Factor Surveillance System (BRFSS) state governments can further address Alzheimer's in their states.

2

BUILD A DEMENTIA-CAPABLE WORKFORCE

As our nation ages more people will develop Alzheimer's and need quality care, however a shortage of qualified health care workers could jeopardize care for individuals living with Alzheimer's and other dementias. State governments need to implement policies that will create incentives and career pathways to recruit and retain health care professionals, require competency-based dementia training for all involved in the delivery of care, and require training of adult protective services workers and law enforcement about how to recognize and interact with individuals living with dementia.

3

INCREASE ACCESS TO HOME AND COMMUNITY-BASED SERVICES

People living with dementia and their caregivers often prefer to keep the individual living in the home for as long as is manageable. In fact, 70 percent of people with Alzheimer's live in the community. State governments can reduce long-term costs and increase access to person-centered care in home and community settings including respite and adult day care, regardless of age or financial status through Medicaid and other state-supported programs.

4

ENHANCE THE QUALITY OF CARE IN RESIDENTIAL SETTINGS

Alzheimer's requires a wide range of evolving care and services, and as the disease advances individuals often need to move into residential settings for more specialized care. In fact, among individuals with Alzheimer's, 75 percent will be admitted to a nursing home by the age of 80. It is important that state governments have in place laws to protect people with dementia from improper displacement in residential settings. State governments must also increase Medicaid reimbursement rates to reflect the higher cost of care for individuals living with Alzheimer's and other dementias to ensure residential care settings remain accessible to the population and their needs.



STATE ADVOCACY 101

Even in these virtual times, state advocacy 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.

GET TO KNOW YOUR STATE LEGISLATORS

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 meetings. For full-time legislatures, recesses come at intervals throughout the year. Join the mailing list for your state legislators. This will allow you to find out about and attend community events, especially virtual town halls where you can speak publicly on Alzheimer's issues and raise awareness.

PARTICIPATE IN STATE ADVOCACY EVENTS

Your state advocacy day provides an opportunity to increase the Association's presence in the state capital and to build relationships with state policymakers. These events bring advocates together to ask lawmakers to support critical policies impacting those living with Alzheimer's. Learn about your state advocacy day and priority legislation at alzimpact.org.



ALZHEIMER'S
STATE CHAMPION

BECOME AN ALZHEIMER'S STATE CHAMPION

By cultivating deep one-on-one relationships with every member of Congress, Alzheimer's Ambassadors have been instrumental in quadrupling federal Alzheimer's research funding since 2011. Alzheimer's State Champions are volunteers working to replicate that successful model in every state by developing multifaceted, year-round relationships with targeted state officials.

Alzheimer's State Champions participate in state advocacy events and have at least two more interactions with their assigned legislator each year. They also stay in touch year-round through social media posts, letters-to-the-editor and other personal communications with their legislators. You can be the voice for thousands of families living with dementia in your community and can help ensure that our leaders stand up for the vital programs and services that they rely on.

Visit alzimpact.org/volunteer to learn more.





WAYS TO SAY THANK YOU

Frequent thank yous, particularly in public settings, are the key to building lasting and mutually beneficial relationships with your legislators. Thank them for meeting. Then thank them for agreeing to your asks. There's always something to thank them for.



BE SOCIAL

Ask for a photo/screenshot of a virtual meeting and promptly post on social networks, “tagging” or “mentioning” your legislator.



HANDWRITTEN NOTES

ALL attendees should send cards to each legislator/staffer they met. Add a personal story and/or photo!



RECORD A VIDEO

Record a brief 20–30 second video of yourself mentioning your legislator and share on your favorite video platform.



LOCAL MEDIA

Work with chapter staff to submit a letter-to-the-editor or write something for your company/community newsletter.



ABAM & TLD

Join virtual meetings during June's Alzheimer's & Brain Awareness Month or invite legislators/staff to join the conversation online.



REPORT YOUR MEETINGS

Please remember to report each meeting at alzimpact.org/action so our staff can follow-up as well!



FOLLOW-UP EMAIL

One attendee should send a prompt follow-up email with requested information, a summary and your thanks.



COFFEES & WALK

Work with chapter staff to plan a virtual “Coffee with Congress” event or invite your legislators to the Walk to End Alzheimer's®.



ADVOCACY ENGAGEMENT PLANNER

Take a moment to plan your advocacy for the year. Consider the follow-up activities and local events that provide opportunities to engage elected officials and fellow advocates.

JAN

FEB

MAR

APR

MAY

JUN

JUL

AUG

SEP

OCT

NOV

DEC

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 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.

- | | |
|---|---|
| <input type="checkbox"/> Meet with elected officials
Lend your voice in district offices, state capitols and at the Advocacy Forum in D.C. | <input type="checkbox"/> Support the Alzheimer's Impact Movement (AIM)
Promote AIM membership. Engage with campaign staff, donors and events. |
| <input type="checkbox"/> Raise awareness through local media
Partner with chapter staff to draft letters-to-the-editor and pitch stories. | <input type="checkbox"/> Call on your connections
Use your relationships with legislators and partner organizations to make calls at key moments. |
| <input type="checkbox"/> Spark social media conversations
Engage online, inspire novices, recruit new advocates and monitor legislator accounts to comment/tweet. | <input type="checkbox"/> Share your unique perspective as a... |
| <input type="checkbox"/> Coordinate events and volunteers
Recruit and mobilize volunteers, organize events and work with event committees. | (person with dementia, researcher, young person, etc). |

Apply online today:

alzimpact.org/volunteer



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.



ALZHEIMER'S ASSOCIATION ALZHEIMER'S IMPACT MOVEMENT

Email info@alzimpact.org
Web alz.org | alzimpact.org
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The Alzheimer's Impact Movement (AIM) is the advocacy arm of the Alzheimer's Association. AIM works to secure policies to overcome Alzheimer's disease, including increased investment in research, improved care and support, and development of approaches to reduce the risk of developing dementia.

Learn more at alzimpact.org.

SIGN UP TO ACT

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