Activist Toolkit
USAgainstAlzheimer’s Activist Toolkit

Table of Contents

Introduction
- Welcome letter from George Vradenburg, Co-Founder of USAgainstAlzheimer’s 1
- How to Stop Alzheimer’s Disease 2
- Five Things You Can Do 3

Learn More: The Facts about Alzheimer’s
- Fact Sheets and Charts 5
  - The Alzheimer’s Health Crisis (Fact Sheet) 6
  - Cost Savings and the Price of Inaction (Fact Sheet) 8
  - Alzheimer’s Disease Projections (Chart) 9
  - NIH Research Funding (Chart) 10
  - Change in Number of Deaths (Chart) 11

Activist Tools, Tips, and Templates
- Organizing Others 13
  - How to Collect Stories 14
    - Sample Story Sharing Email 15
  - How to Use Social Media to Promote Our Fight to Stop Alzheimer’s 16
  - Giving a Speech 17
- Pressuring Policymakers 19
  - Meeting with Your Members of Congress — Before the Meeting 20
  - Meeting with Your Members of Congress — During the Meeting 22
    - Sample Meeting Request 24
    - Sample Meeting Agenda 25
    - Sample Thank You Letter 26
  - How to Call Members of Congress 27
  - How to Collect Letters of Support 28
    - Sample Letter in Support of Increased Funding for Alzheimer’s Research 29
- Talking to the Press 30
  - How to Write and Submit Op-Eds and Letters to the Editor 31
    - Sample Caregiver Letter to the Editor 33
    - Sample Family Member of Individual with Alzheimer’s Letter to the Editor 34
    - Sample Researcher Letter to the Editor 35
  - How to Pitch and Place a News Article 36
  - General Media Outreach Tips 39
- Collecting Signatures for the Stop Alzheimer’s Petition 40

About Us
- USAgainstAlzheimer’s - About Us 42
- USAgainstAlzheimer’s - Frequently Asked Questions 45
Dear Alzheimer’s Activist,

Thanks to activists like you, we are building a movement to stop Alzheimer’s. It’s because of your willingness to speak up that policymakers are beginning to take notice of the immense human and fiscal crisis wrought by Alzheimer’s disease. Yet, as we all know, the stark and tragic reality is that currently there is no cure, treatment or other means of prevention for Alzheimer’s. We cannot accept this status quo. By building a network of engaged and enraged activists in your community, you drive our collective movement forward.

The Activist Toolkit is only one way we hope to support you in your work. As you know, we continue to issue action alerts, suggesting pivotal moments when we think it is important to engage with national lawmakers and others.

But the toolkit provides a focal point. We hope it will support and guide you in organizing others, pressuring policymakers and talking to the press about the urgent need to make stopping Alzheimer’s a national priority. You will find information on Alzheimer’s, its costs, research funding and federal policy, as well as the guidance and documents you’ll need to take action to stop this devastating disease. For example, the toolkit includes information on making appointments with members of Congress and getting the most out of those meetings, using social media to promote the fight to stop Alzheimer’s, and writing letters to the editor, among other topics.

Activists like you are critically important to the movement to end Alzheimer’s. As family members, caregivers and researchers who have seen the personal toll of Alzheimer’s, together we must demand transformative actions to achieve the attainable goal of ending Alzheimer’s by 2020. Mobilizing your community helps build a critical mass of activists who are aware of the devastating effects of this disease. And by working together, we will urge our political leaders to make critical investments in scientific research needed to cure Alzheimer’s.

Thank you as always for your compassion, determination and commitment to this fight. We cannot do it without you.

Sincerely,

George Vradenburg
Co-Founder
USAgainstAlzheimer’s
How to Stop Alzheimer’s Disease

This is a pivotal time for the Alzheimer’s community. Researchers believe it’s possible to prevent or control the disease within 10 years with a disciplined strategy that is adequately funded. To succeed, we need a political strategy that ensures that elected officials and lawmakers make fighting Alzheimer’s a national priority and implement a clear plan for a cure.

Where are we now?

Real progress is being made and the steps we take now will dramatically shape how our nation confronts this crisis. In 2012, the Obama Administration and the U.S. Department of Health and Human Services announced its proposal to increase federal funding for Alzheimer’s research by $80 million dollars over the current fiscal year as one of the concrete steps in support of the United States’ first-ever National Plan to Address Alzheimer’s Disease—a comprehensive roadmap with a bold goal to prevent and effectively treat Alzheimer’s by 2025.

How do we stop Alzheimer’s?

In order to stop Alzheimer’s we must:

- Build awareness among our families, friends, and in our communities of the devastating effects of Alzheimer’s disease;
- Implement a bold plan to stop Alzheimer’s;
- Increase funding for Alzheimer’s research;
- Speed development of new cures;
- Pressure political leaders to keep their promises to support stopping Alzheimer’s disease.

What are the next steps?

For far too long, Alzheimer’s disease has been in the shadows. We can stop Alzheimer’s by educating others about the stark realities of this disease and the impact it has on our nation. Alzheimer’s touches one in three Americans and will cost our nation more than a trillion dollars each year by 2050 if we don’t act now. The National Plan to Address Alzheimer’s Disease recommendations, which call for $2 billion in annual funding for research, and budgetary requests made by the Obama Administration show great progress in establishing a bold plan to stop Alzheimer’s and provide the funding necessary to speed research and delivery of new cures to patients.

For more information, please visit www.usagainstalzheimers.org.
Five Things You Can Do To Stop Alzheimer’s

1. Learn The Facts

This toolkit has all the materials you need so you can speak out about the effect of Alzheimer’s on you, your family and our nation and what needs to be done to stop this devastating disease. The subsequent sections include information about Alzheimer’s disease, the financial cost, and tools and tips to help you speak knowledgeably about why Alzheimer’s must be stopped.

2. Organize Others

Activists like you are the engine that powers this movement to stop Alzheimer’s. By working within your communities, you are building networks of enraged and engaged activists that will help propel this movement forward. Visit www.usagainstaword.org to find out about the urgent, specific ways to join the fight. Also, make sure you’re signed up to get breaking news and actions you can take to help US stop Alzheimer’s. Don’t forget to contact family, friends and organizations in your community about the devastating impact of Alzheimer’s and enlist their help in the fight against this disease.

3. Share Your Story

Connecting with your network – friends, family and organizations in your local community – about Alzheimer’s disease is a great way to engage others in the fight. One in three families is affected by Alzheimer’s, and hearing your story will empower your friends and neighbors to get involved, too. Share your story of how Alzheimer’s has affected your life and ask family and friends to do the same. Together, we can show lawmakers the terrible toll this disease takes on families.

4. Pressure Policymakers

Calling or writing your members of Congress is a great way to influence their opinions on issues and legislation. It only takes a few minutes and is an easy way to educate policymakers and urge them to join you in stopping Alzheimer’s disease.

5. Write a Letter to the Editor (LTE)

Communicate with your local press to educate others about the devastating effects of Alzheimer’s and recruit others to join our efforts. Responding to a previous article by writing a letter to the editor (LTE) can be an effective way to communicate this message in your community.

Need help or advice?
Email takeaction@usagainstalzheimers.org
Fact Sheets and Charts
The Alzheimer’s Health Crisis

What is Alzheimer’s disease?

Alzheimer’s disease is an irreversible, progressive brain disease that slowly destroys memory and thinking skills and eventually is fatal. It is also the most common cause of dementia in older people.¹

Who has Alzheimer’s disease?

Experts suggest that 5.4 million Americans have Alzheimer’s, and there are over 15 million unpaid caregivers of Alzheimer patients within the US. The number of individuals with Alzheimer’s is expected to almost triple, approaching 13.5 million, in the next few decades.² Alzheimer’s disease is the sixth leading cause of death among Americans.³

Without a cure, Alzheimer’s is expected to cost the U.S. $2 trillion by 2020 and have a devastating impact on families who often bear the brunt of the disease

Alzheimer’s has a disproportionate impact on members of the African American and Hispanic communities, who are at higher risk of developing Alzheimer’s. African Americans are about twice as likely, and Hispanics are about 1.5 times more likely to develop the disease than are Caucasians for reasons not yet understood.⁴

What causes Alzheimer’s disease?

Scientists still have not determined the exact cause of Alzheimer’s disease, but studies on plaque and tangles of the nerves within the brain are being conducted. Most people develop late-onset Alzheimer’s in their 60s. There is no cure for Alzheimer’s yet, but there are prescriptions that may temporarily slow the progression of the disease.⁵

What are the costs associated with Alzheimer’s disease?

More than $200 billion is spent annually treating Alzheimer’s, which is more than 400 times the amount spent on finding a cure.⁶

The average annual payments per person for health care, services, and Medicare for beneficiaries aged 65 or older with Alzheimer’s is $43,847, which is more than three times greater than Medicare pays for individuals without Alzheimer’s and dementia. The reason for this cost difference is that the loss of memory due to the disease makes it more likely the victim will otherwise not be able to care for himself.⁷

Every year, American taxpayers spend $200 billion on Medicare and Medicaid expenses related to Alzheimer’s. If substantial progress is not made in stopping Alzheimer’s, Medicare and Medicaid spending will reach $1.1 trillion in today’s dollars by 2050.⁸

Medicaid payments alone are more than nine times higher for those with Alzheimer’s compared to those without. The cost difference is attributed to the institutional care that is necessary in the later stages of the disease due to total dependence. More than 50% of nursing home residents have Alzheimer’s disease.

⁵ ibid
⁶ ibid
⁷ ibid
Who funds Alzheimer’s research?

The National Institutes of Health (NIH) invests over $31.2 billion annually in medical research for the American people. That figure excludes the "one time" appropriation of $10 billion awarded to the NIH through the American Recovery & Reinvestment Act of 2009 (ARRA). In FY 2011, about $448 million was devoted to research related to Alzheimer’s disease. ARRA allocated $10 billion specifically to the NIH. Of that, some of the special initiatives went specifically to Alzheimer’s disease research.9,10

The Alzheimer’s Association International Grant Program has been a major private source of funding. Since awarding its first grants in 1982, the Association has grown into the largest private, nonprofit funder of Alzheimer’s research, awarding more than $265 million to 1,800 best-of-field grant proposals over the last 28 years.11

Is there any current legislation or federal policy to address Alzheimer’s disease?

Legislation will be added as it is introduced in the current Congress. In 2012, the Obama Administration and the U.S. Department of Health and Human Services announced its proposal to increase federal funding for Alzheimer’s research by $80 million as one of the concrete steps in support of the United States’ first-ever National Plan to Address Alzheimer’s Disease—a comprehensive roadmap with a bold goal to prevent and effectively treat Alzheimer’s by 2025. The plan establishes five ambitious goals to both prevent future cases of Alzheimer’s disease and to better meet the needs of the millions of American families currently facing this disease.

- Prevent and Effectively Treat Alzheimer’s Disease by 2025.
- Optimize Care, Quality and Efficiency.
- Expand Supports for People with Alzheimer’s Disease and Their Families.
- Enhance Public Awareness and Engagement.
- Track Progress and Drive Improvement.12

---


Cost Savings and the Price of Inaction

The Financial Strain of Alzheimer’s Disease in the United States

What are we up against?

Alzheimer’s disease, the most common form of dementia, is a progressive, degenerative brain disease that gradually destroys a person’s memory and ability to learn, reason, make judgments, communicate and carry out daily activities.

Alzheimer’s disease is the 6th leading cause of death in the United States, and the only disease in the top ten with no disease-modifying treatment or cure. There are currently 5.4 million Americans with Alzheimer’s—a number that is expected to triple in the coming decades.

For every dollar the federal government spends today on the costs of Alzheimer’s care, it invests less than a penny in research to find a cure.

The Financial Strain

In 2011, American taxpayers spent $200 billion caring for those with Alzheimer’s (more than 400 times the amount spent on finding a cure). By 2050, the annual cost of Alzheimer’s to families, insurers, and the government is projected to explode to over $1 trillion.

Within ten years, we will spend more than $2 trillion on care for Alzheimer’s victims.

The average family caring for a relative with Alzheimer’s can expect to spend $215,000 throughout the entire course of the disease ($40,000 for direct costs; $175,000 for indirect costs).

There are nearly 15 million Americans who currently provide care for a person with Alzheimer’s.

The Price of Inaction

In August 2011, the challenge of lowering the national debt by $2.5 trillion over the next 10 years caused the United States to come within one day of financial default. No one noted during the debate, however, that over the same 10-year period, the country will be forced to spend another $2 trillion caring for Americans with Alzheimer’s disease.

The cost of this care will negate any gains made from government deficit reduction efforts. For the health of our nation’s economy and seniors, we cannot afford or accept this two-steps-forward, two-steps-back approach.

Can we stop Alzheimer’s by 2020?

Yes. The research community believes it is possible to prevent or control the disease within ten years with a disciplined strategy that is adequately funded. To succeed, we need a political strategy that ensures that elected officials and lawmakers make fighting Alzheimer’s a national priority and implement a clear plan for a cure.

USAgainstAlzheimer’s believes strongly that through bipartisan support for innovative ideas that cut through government bureaucracy and streamline funding for research, we can end Alzheimer’s as we know it by 2020.
Alzheimer’s Disease Projections: Incidence, Cost of Alzheimer’s Care, and Federal Research Funding

Cost of Care

People in US with Alzheimer’s

AD Cost of Care

AD Research Funding (current trends)

Number of Americans with AD (millions)

National Institutes of Health Research Funding

- Alzheimer's: $0.45 Billion
- HIV: $3.10 Billion
- Heart Disease: $4.30 Billion
- Cancer: $5.8 Billion

Source: Alzheimer's Association calculations based on NIH data.
Change in Number of Deaths 2000-2008

- Alzheimer's: 66% increase, $0.45 Billion
- HIV: 29% decrease, $3.10 Billion
- Heart Disease: 13% decrease, $4.30 Billion
- Cancer: 23% decrease, $5.8 Billion

Source: Alzheimer’s Association 2011 Alzheimer’s Disease Facts and Figures and Alzheimer’s Association calculations based on NIH data
Activists Tools, Tips and Templates
Organizing Others
How to Collect Stories

Personal stories about how Alzheimer's affects families are a powerful way to show policymakers the people behind the statistics. Stories from individuals with Alzheimer's, family members, caregivers and researchers help bring Alzheimer's out of the shadows and make the case that funding Alzheimer's research must be a national priority.

Your stories also help engage the media by encouraging reporters to write about the disease from the perspective of those who are impacted by Alzheimer's.

How to Collect and Share Stories:

- Visit the USAgainstAlzheimer's website and submit your story of how Alzheimer's has touched your life.
- Contact family, friends and others in your community and ask them to share their stories of how Alzheimer's has affected their lives either through the USAgainstAlzheimer's website or Facebook page or their own Facebook pages and Twitter accounts. A sample story sharing email follows, that you can customize.
- Are you part of an Alzheimer's support group or other Alzheimer's organization? Reach out to those in your local Alzheimer's community and ask them to share their stories.
- Ask your Facebook friends and Twitter followers to share their stories of how Alzheimer's has touched their lives. Below are sample posts that you can customize:
  - Twitter
    - I shared how #Alz has touched my life. Join me & share your story w/ @USAgainstAlz: http://bit.ly/J86L7E #EndAlz
  - Facebook:

Need help or advice?
Email takeaction@usagainstalzheimers.org
Dear [insert name],

Alzheimer's is more than just numbers—it's people: caregivers, families, individuals. But too often, our struggles are experienced in solitude and without recognition of the difficulties Alzheimer's brings. 

We need to share our experiences in order to make a strong public case for an aggressive national effort to stop Alzheimer's. We can't wait any longer.

I shared how Alzheimer's has touched my life. Join me and share your story with USAgainstAlzheimer's. By sharing your story today, you will help bring us one step closer to stopping Alzheimer's.

Thank you,

[Insert your name]
How to Use Social Media to Promote Our Fight to Stop Alzheimer's

Social media is a great way to engage your family, friends and community and make them feel part of your USAgainstAlzheimer's advocacy efforts. Use the social media ideas below to connect with your Facebook friends and Twitter followers about our fight to stop Alzheimer's.

Follow USAgainstAlzheimer's on Facebook and Twitter
- Ask your Facebook friends and Twitter followers to follow USAgainstAlzheimer's on Facebook and Twitter
- Share and retweet our posts on your Facebook page and Twitter account

Before Events and Meetings
- Are you scheduling a meeting with your member of Congress? Ask your Facebook friends and Twitter followers to join you.
- Will you be meeting with an elected official? Find elected officials' Facebook pages and Twitter handles so you can mention them in your posts about the event or meeting.
- Remember to post pictures with your status updates to make sure your followers see them!
- Tag the USAgainstAlzheimer's Facebook page when posting about events or meetings.

Examples:

Twitter: Going to meet [elected official's Twitter handle] to discuss #Alz on [insert date]. DM me if you'd like to join!

Facebook: Just scheduled a meeting with [elected official's Facebook Page] to discuss the impact of Alzheimer's on our country. If you'd like to join, let me know!

Promoting Advocacy
- Use the hashtag #AlzActivist when tweeting about your advocacy activities.
- If you have a Letter to the Editor or opinion piece published, share the link with your Facebook friends and Twitter followers.
- If you have a smart phone, post pictures or video and share stories from your event or meeting with your friends and followers. Include who you're meeting with and what you're talking about. Make them feel like they're there with you.

Examples:

Twitter: The [insert newspaper's Twitter handle] just published my LTE on #Alz crisis [insert link]! #EndAlz

Facebook: Just had a great meeting with [elected official's Facebook Page]! We talked about the impact of Alzheimer's on our nation. Click "LIKE" if you want to stop Alzheimer's!

After Events and Meetings
- Upload your photos from the event or meeting to a Facebook album.
- Mention a local reporter you know in a tweet to help create a dialogue so that you can go back to them later with information about an event you are holding, an action you took. For example, if @JessJonesWDJ is a health reporter at the Mountain Daily Journal, your first tweet to her could be something like: Thx @JessJonesWDJ for your great story on #Alz last week. A must-read! #endalz
- Thank the elected officials you met with by posting a thank you on the official's Facebook wall and tweeting a thank you to their Twitter handle.

Examples:

Twitter: Last week we met with [elected officials Twitter handle] to discuss the impact of #Alz. Join me & send a message with @USAgainstAlz http://bit.ly/GQZ6uV

Facebook: Thanks [elected official's Facebook Page] for meeting with us last week! Click "LIKE" to thank the Rep. XX for supporting stopping Alzheimer's!

USAgainstAlzheimer's will be posting on Facebook and Twitter (@usagainstalz) about our campaign, so make sure to share and retweet our posts! We will also be on the lookout for your pictures to share.

If you have any social media questions, email takeaction@usagainstalzheimers.org.
Giving a Speech

Speaking about Alzheimer’s and how it has affected you and your family is an effective way to raise awareness about the toll this disease takes. These Talking Points will provide you with guidance whether you are speaking before a group in your community or in a larger setting.

(Bold = Highlights/Sound-bites)

The Crisis

- Alzheimer’s is shaping up to be the great health crisis of the 21st century.

- Currently, 5.4 million Americans suffer from Alzheimer’s the 6th leading cause of death in America, and the only disease in the top ten with no cure or disease-modifying treatment. In Texas alone, there are 340,000 people who suffer from Alzheimer’s.

- Alzheimer’s kills more Americans each year than breast cancer and prostate cancer combined.

- Unfortunately, there’s a prevailing almost defeatist view that Alzheimer’s is an insurmountable problem or even worse, an inevitable and natural part of aging.

- But in reality, while Alzheimer’s is a cruel and devastating disease, researchers believe it can be stopped by 2025 with the renewed national commitment and sufficient resources.

- Together, as a nation, we’ve accomplished incredible feats sending a man to the moon, curing polio, and mapping the human genome. If we set our minds, our energy, and our hearts to this, we can once again achieve the improbable.

- If left unchecked, Alzheimer’s and other dementias will cost the U.S. $2 trillion over the next decade. By 2050, Alzheimer’s and other dementias will cost the U.S. $1 trillion annually (and yet NIH only spends on Alzheimer’s research around $90 per person living with the disease).

- To put that in perspective, research funding for Alzheimer’s is less than 0.3 percent of medical care cost for the disease. For cancer, it’s 3 percent; for HIV/AIDS, it is 20 percent.

The Fight Against Alzheimer’s

- Alzheimer’s has affected me profoundly (insert personal impact) and I want to personally do something to stop Alzheimer’s.

- I have joined a group called USAgainstAlzheimer’s, a group committed to mobilizing America to demand the necessary actions by our national leaders to find a cure to this disease.

- USAgainstAlzheimer’s was founded by George and Trish Vradenburg two leaders who also have been touched by the disease in order to be a disruptive force against the status quo, “business as usual” approach to stopping the disease.

- USAgainstAlzheimer’s is made up of a nationwide community of activists and influencers who are working together to build momentum and urge elected officials and other decision makers to get serious about stopping the disease.
Reason For Hope

- Fortunately, the movement to stop Alzheimer’s has more momentum than it ever has before with researchers, industry, and government coming together to fight Alzheimer’s disease – first ever national goal.

- And with a groundswell of support from a community of Alzheimer’s activists, which includes USAgainstAlzheimer’s, we are raising our voices to ensure that Washington joins our fight and recognizes that we can no longer ignore the Alzheimer’s crisis.

- The ActivistsAgainstAlzheimer’s Network is the powerful, united voice of enraged and engaged Alzheimer’s advocates working to commit our nation to a bold and aggressive plan to prevent and treat Alzheimer’s disease.

Call to Action

- All of us are in some way affected by Alzheimer’s – if not personally then as taxpayers who have to pay for increasing care.

- I ask each of you to join me in this fight.

- There is one simple thing you can do now. Please visit stopalznow.org and sign the Petition calling on the President and Congress to dedicate all resources necessary to fulfill the commitment of the National Plan to Address Alzheimer’s Disease.

- Once you do that, you will be a part of our team, a part of our fight, a part of a historic and unprecedented effort to stop this tragic disease.

Need help or advice?
Email takeaction@usagainstalzheimers.org
Pressuring Policymakers
Meeting with Your Members of Congress – Before the Meeting

One of the most effective ways to influence the policymaking process and build relationships is to meet with your members of Congress, or their staff, in person. Members of Congress return to their districts/states frequently throughout the year. Visit your member’s website to find the contact information for their district offices.

Put in a Request for a Meeting

First, you must request a meeting from the Congress member’s scheduler. You should make this request by email or fax (so that it is in writing). Then follow up the initial request immediately with a phone call, since schedules may be tight. Many congressional offices now also make it possible to request a meeting on their websites.

TIPS:
• Suggest specific times and dates for the meeting.
• Let the contact person know you’d like to discuss why stopping Alzheimer’s disease should be an urgent priority for our nation.
• If the lawmaker is unavailable to meet with you, ask for a meeting with the staff member responsible for health issues.
• If you have a previous relationship with your member of Congress or their staff, mention it right away. Are you members of the same alumni association? Board of Directors? Did you attend a fundraiser or volunteer for their campaign?
• Be respectful but be persistent! Make sure to follow up with the office if they don’t get back to you. If they say they have no availability, call back in a couple of days and ask if there have been any cancellations.

Prepare for Your Meeting

1. Do your homework.

First, find out where your lawmaker stands on USAgainstAlzheimer’s policy priorities or if they are a member of important committees like Health, Education, Labor, and Pensions or Appropriations. Visit the lawmaker’s website to find information on their positions on increasing funding for Alzheimer’s research, any remarks they have made addressing the Alzheimer’s crisis and for committee assignments.

2. Provide materials to support your position.

Once you’re familiar with your lawmaker’s positions and where the legislation stands, the next item on your agenda is assembling the materials you will need for your visit.

The Learn More section of this toolkit contains the written information that you will provide to the lawmaker or his or her staff. Bring copies of the fact sheets with you to leave behind with them!

3. Recruit attendees

Inviting friends, family, fellow activists and leaders from local health or caregiving organizations can be a great way to engage them in this campaign. They can also provide additional expertise and information to your lawmaker and show that the community supports stopping Alzheimer’s and increasing funding for Alzheimer’s research. If no one else is available to join you, one-on-one meetings are still extremely helpful.
4. **Confirm and prepare for your meeting**

It’s important that you confirm your meeting with your lawmaker a couple of days before the meeting is to occur. You may also use this opportunity to schedule a follow-up meeting or conversation with a staff member to see if they need any additional information or have any updates following your visit.

Also, make sure to prepare for the meeting in advance and go over what you’d like to say during the meeting – you can practice with a friend or family member. If you’re bringing others with you to the meeting, divide up roles among the group to make sure you are all on the same page about who will lead the meeting and who is responsible for what talking points. We recommend bringing a small packet of information for your lawmaker, including fact sheets from this toolkit, any recent/relevant local press clips or event coverage, and any constituent or organizational sign on letters.

**Need help or advice?**

Email [takeaction@usagainstalzheimers.org](mailto:takeaction@usagainstalzheimers.org)
Meeting with Your Members of Congress – During the Meeting

- **Acknowledge support** - Take a moment to acknowledge the lawmaker’s current support for any legislation he or she is already co-sponsoring or any past support he or she has given. Saying thank you is an important way to win further support.

- **Paint the big picture and the small picture** - For example, one person might tell his or her story about how the proposed increases in funding for Alzheimer’s research could affect him or her personally (the small picture). Someone else could review current statistics and the impact that Alzheimer’s disease has in the United States and your state specifically (the big picture).

- **Tell your story** - The most effective method of communicating the need for increased funding for Alzheimer’s research and why stopping Alzheimer’s should be a national priority is to tell your personal story. We have seen time and time again that personal stories change minds, and this is your chance to sell the need to stop Alzheimer’s.

- **Make specific, clear requests and ask for an answer** - Often, the main reason groups have unsatisfactory meetings is that their requests are not clear and specific enough. Your elected officials need to know specifically what you want them to do (e.g. increase funding for Alzheimer’s research).

- **Be a resource for the policymaker and his or her staff** - As an activist devoted to finding a cure for Alzheimer’s, you offer a unique perspective. Offer your time and assistance if he or she or a staff member wants to talk about your areas of interest and expertise in the future.

- **Provide material to support your position** - Leave the office your contact information, a fact sheet and any relevant Letters to the Editor (LTE’s) that have been published in your local newspapers. If your policymaker has specific question that you can’t answer, promise to follow up with them later.
Meeting with Your Members of Congress – After the Meeting

- **Follow up immediately with a thank you letter or email** - Be sure to include any additional information you may have promised or that may be relevant to the issue. If you had others in the meeting with you, make sure you coordinate following up so that nothing slips through the cracks.

- **Tell USAgainstAlzheimer’s about your meeting** - Send a short email to takeaction@usagainstalzheimers.org describing:
  
  - Who you met with
  - The date and location of the meeting
  - What you discussed
  - Follow up that needs to take place

  This information is important in our continued communications with members of Congress.

- **Post about your meeting on Facebook and Twitter** - Share with your friends and followers your favorite part of the meeting. Review the social media guide in this toolkit for sample posts.

- **Stay in touch with your member of Congress** - This is only the beginning of a hopefully long, fruitful relationship! Reach out to the staff member or member of Congress that you met with from time to time, to remind him or her that you are still paying attention. Ask if there are any updates. Call the office before any big votes that affect funding or research on Alzheimer’s. Stay tuned to action alerts from USAgainstAlzheimer’s – we’ll help you stay abreast of what’s happening on Capitol Hill and ways to leverage the relationship you’ve begun.

Need help or advice?  
Email takeaction@usagainstalzheimers.org
Sample Meeting Request

[Date]

The Honorable [Insert your Representative or Senator's first and last names]
[Insert the office address]
[Insert the office city, state and ZIP Code]

Dear [Representative [OR] Senator Insert your Representative or Senator's last name],

[I/We am/are] writing to request a meeting with you at your district office in [insert the name of the city where you'd like to meet] on [date or timeframe]. [I/We] would like to discuss why stopping Alzheimer's disease should be an urgent priority.

As your constituent(s) and [an activist/activists] devoted to finding a cure for Alzheimer's [who has/have been] touched directly by Alzheimer's, [I/we] would like the opportunity to talk to you about the importance of addressing the Alzheimer's crisis now. [I am/we are] fearful of the impact Alzheimer's will have on [my/our] [family/families], state and country. Alzheimer's is the 6th leading cause of death in the United States and there are currently 5.4 million Americans with Alzheimer's, a number that is expected to triple over the next decade. American families and taxpayers spend $200 billion per year caring for those with Alzheimer's and in ten years time, more than $2 trillion will have been spent on care for Alzheimer's victims. [I/We] would like to discuss how you can help alleviate the burden of Alzheimer's and other high-cost chronic diseases on families in our [state/district] in the near future and help cure this devastating disease.

[I/We] will follow up in the next few days with a phone call to schedule this meeting. If you have questions, please feel free to contact [me/us] at [Insert your phone number or e-mail address].

Sincerely,

[Insert your first and last name/s]
[Insert your address/es]
[Insert your city/ies, state and ZIP code/s]
Meeting with Your Members of Congress – Sample Meeting Agenda

Section 1: Introductions

- Introduce USAgainstAlzheimer's briefly.
- Allow participants to say who they are and what they do in the community. Emphasize any commonalities they have with the member – for example, same alma mater, a part of the same business industry.
- Ask the member of Congress and/or aides a question, to help get to know them better and break the ice. It can be topical, such as, “Has anyone in your life been affected by Alzheimer’s?” or more general, such as, “How long have you worked for [member]?” or “Did your kids go to [local school district]?”
- Briefly outline the issues you are there to discuss.

Section 2: Acknowledgements

- Acknowledge your member of Congress for any previous actions.
- If your group needs information about a specific representative or senator, email takeaction@usagainstalzheimers.org for help preparing and looking up past voting records.

Section 3: Brief them on the issue

- Explain national statistics to underscore that Alzheimer’s is a major, national crisis. Highlight the economic and social impact of Alzheimer’s.
- Have someone tell a personal story and wrap that story into statewide or regional statistics. Practice this so that it comes across smoothly. Example: “My mother is an Alzheimer’s patient. Two years ago, she was a healthy, proud grandmother. Nowadays, she barely recognizes me and won’t talk to her grandchildren. My family spends thousands of dollars per month on her care, and it’s starting to take its toll. But it’s not just me. In [state] alone, [percentage] of residents are currently suffering from Alzheimer’s. Thousands of people just like me are struggling to make ends meet, which is why I’m here. We need your help.”
- Ask if the member knows the status of a current piece of legislation or issue in Congress. If not, explain it if possible.

Section 4: Make an “ask”

- What was your goal going into this meeting? Do you need the member of Congress to cosponsor a piece of legislation? Vote a certain way on specific legislation? Support something in committee? Host a Congressional hearing or briefing? Now is the time to directly ask him or her to take a specific action.

Section 5: Plan for follow-up

- Set a specific timeline for follow-up with the congressional staff and ask if there is any specific, additional information they need. Be sure to have someone record your plan for follow-up.
Sample Thank You Letter

[Date]

The Honorable [Insert your Representative or Senator's first and last names]
[Insert the office address]
[Insert the office city, state and ZIP Code]

Dear [Representative [OR] Senator Insert your Representative or Senator's last name],

Thank you for making [insert name of person you met] of your staff available to visit with [me/us] on [date]. [I/We] appreciate the time given to [me/us] and the cordial exchange we had with [him/her].

[I am an activist with USAgainstAlzheimer's/USAgainstAlzheimer's activists participated in the visit] and [I/we] discussed why stopping Alzheimer's disease should be an urgent priority for our nation and [insert other topics discussed]. As [an activist/activists] devoted to finding a cure for Alzheimer's [and/many of us] touched directly by Alzheimer's and fearful of the impact it might have on [my family/our families], state and country [I/we] urge you to support [my/our] goal of stopping Alzheimer's disease. There are currently 5.4 million Americans with Alzheimer's, a number that is expected to triple over the next decade. American families and taxpayers spend $200 billion per year caring for those with Alzheimer's and in ten years time, more than $2 trillion will have been spent on care for Alzheimer's victims

[Insert personal story to illustrate how Alzheimer's has impacted your life].

I/We sincerely hope you will support legislation that will help alleviate the burden of Alzheimer's on families in [state/district] in the near future and that will help cure this devastating disease.

Sincerely,

[Insert your first and last name/s]
[Insert your address/es]
[Insert your city/ies, state and ZIP code/s]
How to Call Your Members of Congress

Calling your members of Congress or their staffs is an effective way to influence their opinions about issues or legislation. Members of Congress regularly ask their staffs to report on the opinions of constituents calling their offices and often keep track of the numbers of constituents weighing in on a particular issue.

To call your Senators' and Representative's Washington, D.C. offices, call the U.S. Capitol Switchboard at 202-224-3121. You can find out who your Senators or Representative are, as well as access their contact information, using these online lists and tools: http://house.gov/htbin/findrep?ZIP= for the House and http://www.senate.gov/general/contact_information/senators_cfm.cfm for the Senate.

What to say when you reach the lawmaker's office:

Hello, my name is [your name] and I am a constituent and Alzheimer's activist in your [state/ district].

I am calling today to urge Senator / Rep. _____ to do more to stop Alzheimer's disease.

Alzheimer's is the 6th leading cause of death in the United States and there are currently 5.4 million Americans with Alzheimer's, a number that is expected to triple over the next decade. American families and taxpayers spend $200 billion per year caring for those with Alzheimer's and in ten years time, more than $2 trillion will have been spent on care for Alzheimer's victims.

As a constituent, this issue matters to me because ______________[share your personal reasons for getting involved in the fight against Alzheimer's]_______________________.

I hope Senator / Rep. _____ will make Alzheimer's the urgent priority it needs to be if we are to find a cure by 2020.

[Leave your name, home address and phone number so the office can follow up with you.]

Need help or advice?
Email takeaction@usagainstalzheimers.org
How to Collect Letters of Support

One of the most effective ways to educate and influence elected officials is to persuade local community leaders and influential organizations to write letters in support of USAgainstAlzheimer’s policy goals. These letters show the broad support for stopping Alzheimer’s within the official’s community.

For example, you might ask local or state officials to write letters to your member of Congress describing the impact Alzheimer’s disease has had in your community, or collect letters from the heads of local caregiver organizations to be delivered at an in-district meeting or lobby day. Please do not mail these letters; always send them electronically or deliver them at an in-person event as mail to the U.S. Capitol takes a very long time!

Below are some tips on how to write an effective sign-on letter that you may find helpful when asking individuals and organizations to write letters. You will also find a template letter in support of increased funding for Alzheimer’s disease research that can be customized.

Tips for Writing an Effective Sign-on Letter

• The organization should print the letter on their letterhead or include the individual’s return address at the beginning of the letter. Members of Congress and state legislators receive hundreds of letters every year from many different individuals and organizations. The address shows the office that the writer is a constituent, which lends weight to his or her argument.

• Although you will send these letters electronically or deliver them in person, use the correct title and mailing address for your member of Congress. If the organization or individual is addressing the letter to more than one elected official, include a mailing address for each official. Below is a guide to addressing the letter:

  The Honorable [Full Name of Representative]
  United States House of Representatives
  Washington, DC 20515

  The Honorable [Full Name Senator]
  United States Senate
  Washington, DC 20510

• Make sure that personal stories or state-specific information are included in the letter. The template is simply a starting point. When asking for letters, remind the writers to customize the template based on their experiences with Alzheimer’s disease. Personalized information enhances their arguments and gives elected officials background on the devastating impact Alzheimer’s has on families and communities.

• Remind writers to check spelling and grammar. Even the smallest mistakes can lower the credibility of their argument.

• Ask the organizations or individuals to send you a final copy of the letter. Copies of the letter are useful for you to use during meetings with elected officials as evidence of the community support around the USAgainstAlzheimer’s campaign.

Need help or advice?
Email takeaction@usagainstalzheimers.org
Sample Letter in Support of Increased Funding for Alzheimer’s Research

[Date]

The Honorable Members of the United States House of Representatives
Washington, DC 20515

The Honorable Members of the United States Senate
Washington, DC 20510

Dear [Member of Congress]:

As activists devoted to finding a cure for Alzheimer’s - many of us touched directly by this devastating disease and fearful of the impact it might have on our families, state and country - we are writing to urge you to support increased funding for Alzheimer’s disease research.

Alzheimer’s disease is the 6th leading cause of death in the United States, and the only disease in the top 10 with no disease-modifying treatment or cure. There are currently 5.4 million Americans with Alzheimer’s - a number that is expected to triple in the coming decades. In addition, nearly 15 million Americans serve as unpaid caregivers to loved ones who suffer from the disease, and Alzheimer’s is estimated to cost our nation $200 million this year alone, 70 percent of which will be borne by Medicare and Medicaid.

For every dollar the federal government spends today on the costs of Alzheimer’s care, it invests less than a penny in research to find a cure. Unless a cure or treatment is discovered, the cumulative cost to care for Americans with the disease over the next 10 years will amount to $2 trillion - $20 trillion over the next 40 years. Alzheimer’s disease and other high-cost chronic conditions pose significant challenges to the public health and fiscal health of the nation.

We have two fundamental choices when it comes to paying for Alzheimer’s and other high-cost diseases. One choice is to incur ever-increasing health care expenditures projected to exceed, in the case of Alzheimer’s disease alone, $1 trillion annually by 2050. The second is to increase funding for Alzheimer’s research and accelerate the discovery and development of therapies to prevent and effectively treat the disease, enabling patients to live healthier and more productive lives.

However, the research community believes it is possible to prevent or control the disease within 10 years with a targeted and appropriately funded strategy. For the first time, a Presidential Administration has made Alzheimer’s disease a budgetary priority. In spring 2012, the Obama Administration announced its proposal to increase by $80 million federal funding for Alzheimer’s research, part of a larger two-year effort to increase funding for Alzheimer’s research and clinical care by more than $130 million. This proposed increase in funding is a modest first step, but if we are to meet the goal of preventing and effectively treating Alzheimer’s in the next decade, Congress must eschew a “business-as-usual” approach and tackle Alzheimer’s with the urgency and aggressiveness it requires. If we don’t act, we stand to lose millions more lives and trillions of dollars to this disease.

We, the undersigned organizations, urge you to support increased funding for Alzheimer’s disease. Chronic diseases don’t know politics. Help alleviate the burden of Alzheimer’s and other high-cost chronic diseases on families across the country in the near future and help cure this devastating disease.

Sincerely,

[Individual/Organization Names]
Talking to the Press
How to Write and Submit an Opinion Piece and Letters to the Editor

Placing opinion pieces or letters in local newspapers can be an influential way to insert your viewpoint into an ongoing conversation, or one you want to generate in the community. There are two primary types of opinion pieces you can write. An op-ed is a newspaper article that expresses an opinion about an issue in the news. The name “op-ed” comes from its usual location in the paper, opposite the editorial page. A letter to the editor (LTE) is a letter written to a newspaper by a reader in order to respond to a previous article or topic covered, or to offer a newsworthy opinion.

How to Write and Submit an Op-Ed:

Step 1: Choose when to submit an op-ed. Op-eds are most likely to be published when there is a public debate or coverage of a particular issue occurring (e.g., perhaps around the rapid growth of Alzheimer’s). In some cases they may also be tied to events, however those pieces are generally more difficult to place if they do not have a strong and relevant news hook. The most important rule to follow on submissions is to submit in a timely fashion, before it’s too late—news goes stale very fast.

Step 2: Choose what to write in an op-ed. Many regional newspapers receive opinion pieces with a national angle from newspaper syndicates, so it’s best to emphasize a local or regional angle if possible (e.g., a personal story, local statistic and/or a local event).

Step 3: Write the op-ed. Op-eds should clearly articulate the problem at the beginning of the piece (e.g., the threat of Alzheimer’s is rapidly expanding). Then narrow the arguments down to a regional point (e.g., [State] has XX amount of people afflicted with Alzheimer’s). Conclude with a clearly defined call-to-action (e.g., voters must urge Congress to make finding a cure for Alzheimer’s a top priority).

Step 4: Choose who should ‘sign’ an op-ed. Think through who should sign the op-ed and determine if it might be more advantageous for a particular person to editorialize on the subject. Local activists, regional leaders or organization heads that support our issues are ideal people to consider as signers, or cosigners, of the opinion piece once it is written. The op-ed’s byline might not always belong to the person who wrote it.

Step 5: Check your word count. Newspapers and online outlets have different word count requirements for op-eds. But, in general, it is best to keep them between 650-700 words. Check the outlets’ websites for information about word count requirements, as this information is usually listed in their editorial sections.

Step 6: List your information. Always include your credentials and contact information, as most publications will require verbal or written verification that you have authored the piece.

Step 7: Follow-up after you submit. If you have not heard back from the publication within two days, it’s a good idea to follow-up by phone or e-mail. If the publication is not accepting your op-ed then you should consider submitting to another local paper or online outlet. Also consider posting your piece on a blog that covers the topic or regional issues.
How to Write and Submit a Letter to the Editor (LTE):

Step 1: Choose when to submit an LTE. LTEs are most often accepted when they are written in response to an article or editorial and either point out an alternate perspective or strengthen the original piece. In some cases you can submit an LTE that does not relate to a particular article, but rather highlights a recent local event (e.g., charity event to raise money for Alzheimer’s research). As with op-eds, timing is important—news goes stale very fast, so submit LTEs as quickly as possible.

Step 2: Choose what to write in an LTE. LTEs should be able to stand on their own and make sense to readers who may not have read the original article to which it is responding.

Step 3: Write your LTE. LTEs should be focused and direct. Trying to cover several topics and making too many points reduces your letter’s impact, so try to keep to one subject. If you are responding to an article/editorial/opinion piece, try to reference it in the beginning of the letter.

Step 4: Be brief. Newspapers and online outlets have different word count requirements for LTEs. But in general it is best to keep them as short and succinct as possible (usually between 150-250 words).

Step 5: List your information. Always include your credentials and contact information, as most publications will require verbal or written verification that you have authored the piece.

Step 6: Follow-up after you submit. Most newspapers have areas online where you can post comments to articles. If your LTE does not get placed, consider going online and adding your letter as a comment to a story.

Need help or advice? Email takeaction@usagainstalkzheimers.org
Sample Caregiver LTE

Remember: letters to the editor should be short (150-250 words), timely, and respond to an article, topic covered, or local event. For more tips on writing letters to the editor, click here.

To the editor:

As one of the 15 million caregivers for patients with Alzheimer’s in the U.S., I [agree with/disagree with] what [name] mentions in [his/her] story, [title and date]. I see firsthand the devastation this disease has on its victims and their families as they watch their loved ones lose their ability to [provide examples].

Currently, there are 5.4 million people nationwide suffering from Alzheimer’s including [insert number of those with Alzheimer’s in your state] [State]. The number of Alzheimer’s victims is expected to triple in the upcoming decades and the costs of caring for them will soar.

The stark and sad reality is that currently there is no cure, treatment or other means of prevention for Alzheimer’s. We shouldn’t have to accept this status quo. Without greater urgency and a clear plan of action to find a cure, we will soon be swallowed by the oncoming tide of an aging population. We do not need (nor can we afford) more nursing homes or caregivers like me – what we need is a cure.

We must urge our members of Congress to make finding a cure for Alzheimer’s the national priority it ought to be.

[Name]
[Contact Information]
Sample Family Member LTE

*Remember: letters to the editor should be short (150-250 words), timely, and respond to an article, topic covered, or local event. For more tips on writing letters to the editor, click here.*

To the editor:

In [year], my [family member] was diagnosed with Alzheimer’s disease. Soon afterwards, the person who [raised me, supported me, etc.] faded away until all that was left was a [man/woman] who could no longer [describe problems that occurred as a result of the disease].

Alzheimer’s is a cruel disease that strikes one-in-eight Americans by age 65 and [insert number of those with Alzheimer’s in your State] [State]. Despite the fact that we face an ever growing Alzheimer’s crisis, there is an abundant lack of leadership or urgency to defeat this disease.

Of the ten leading causes of death, only Alzheimer’s has no cure, treatment or other means of prevention. Even so, the National Institutes of Health invests only about $450 million per year toward Alzheimer’s research – less than $90 per person living with the disease.

I believe that we can defeat Alzheimer’s and prevent other families from enduring the pain of seeing their loved ones slip into the shadows of the disease. American ingenuity led to a cure for polio and we can do it again for Alzheimer’s. We must urge our members of Congress to make finding a cure for Alzheimer’s the national priority it ought to be.

[Name]
[Contact Information]
Sample Researcher LTE

Remember: letters to the editor should be short (150-250 words), timely, and respond to an article, topic covered, or local event. For more tips on writing letters to the editor, click here.

To the editor:

[Insert short explanation of your work and the results you hope to achieve]. Researchers and medical experts are doing important work in [State] around Alzheimer’s – a cruel disease that afflicts one-in-eight Americans by age 65 and [insert number of those with Alzheimer’s in your State] [State].

The sad reality is that of the ten leading causes of death, only Alzheimer’s has no cure, treatment or other means of prevention. Despite this, the National Institutes of Health invests only about $450 million per year toward Alzheimer’s research – less than $90 per person living with the disease.

The research community believes that it is possible to prevent or control this disease within ten years with a disciplined and adequately funded strategy. Right now, that strategy and a sense of urgency is nowhere to be found. With increased awareness and leadership, I have no doubt that we can find a cure for Alzheimer’s just as we did for polio.

We must urge our members of Congress to support Alzheimer’s research so we can make finding a cure the national priority it ought to be.

[Name]
[Contact Information]
How to Pitch and Place a News Article

Getting an issue covered in the press is a critical component of any advocacy effort. Media coverage increases public education and awareness, and gives your cause more power in the eyes of opinion leaders and policymakers. When members of Congress know their constituents are concerned and informed about an issue, they are more likely to pay attention to it themselves.

To get press coverage, there are several approaches you can use to reach out to reporters and editorial boards about placing a news article.

Step 1: Choose an outlet for your story. You should target individual reporters and editorial boards from specific outlets and convince them to cover your report release, announcement or event. Make a list of the different outlets where people in your area get their news, including newspapers, radio, television, and the internet. Determine which are the most popular or influential sources. Then start a list of journalists from those media outlets who are writing or speaking about issues related to your Alzheimer’s-related release, announcement, or event.

Step 2: Compile a media list. Your media list should contain the contacts’ names, outlets, coverage areas (“beats”), emails, telephone numbers, and a notes section where you can add relevant updates about the contacts. The best way to build a media list is to evaluate who is already covering the issue(s) you are focused on. Look for reporters writing about the local workforce, politics, health, or national budget.

One approach is to include every writer at a particular news outlet on your list and hope that a release or advisory sent to all of them will reach a few relevant contacts. The best approach is to make a list of the most promising reporters and pursue those contacts. A media list is a work in progress. You should always be adding to and updating it according to the media coverage on your priority topic, whether it is health and family issues, aging research, business or other areas related to Alzheimer’s.

Step 3: Identify the best news hook. To get a reporter’s attention, think about what makes your announcement, report release or event unique, exciting and relevant to the issues that news outlets are covering in your area. Reporters and readers love a narrative—a storyline that helps them understand why something is new and different. Also, putting a person’s face to a news story makes a difference, so be sure to highlight any real people associated with the story arc you decide to pitch (e.g., a caregiver who works with patients suffering from Alzheimer’s). You are more likely to get coverage by focusing on your local story—the local event, the local people involved, the local statistics, and why the issue matters to your community.

Step 4: Write the press release. A press release is a written account of your announcement, report release, or event that provides details, commentary, quotes, and basic background about USAgainstAlzheimer’s and the issues you want to present to the media. Anything included in a press release is considered material a reporter could include verbatim in a story he or she decides to write, thus it’s essential to develop interesting and salient quotes and descriptions. It should provide a thorough summary of your announcement, report, or event, with quotes from your spokespeople and any other local leaders whose support would be valuable.

At the top of your press release, include the words “For Immediate Release” to tell reporters the information is now public. Also include your contact information. Next, include a headline that is to-the-point and intriguing. You can also add a sub-title in italics to add more context to the headline. Then begin the body of your press release. Be sure to lead with the most important and newsy paragraph and don’t forget your news hook. Then support your argument with quotes and relevant background information.

Step 5: Send out your press release. Your press release should generally go out the day of your announcement or event. A release can also be embargoed meaning it can be sent out in advance of
Step 6: If you're having an event, send a media advisory. A media advisory is different than a press release; it is sent in advance of an event to urge the media to attend. The advisory should clearly tell the media what the event is focused on, where and when the event is going to be, who will be there, and why the event is being held, so they have the necessary information to research and send a reporter to your event.

A typical media advisory has the professional look of a press release with your contact information at the top and an attention-grabbing headline. The body of the advisory more closely resembles an invitation, and should very plainly list the information you want the reporter to know.

An advisory should be sent approximately 4-7 days in advance of your event (or earlier if you’re sending it to a weekly paper). Once you pass it along to your targeted media outlets, it’s best to follow up with a phone call 1-2 days prior to the event and then on the day of the event to find out if someone will be able to attend. During or immediately after the event takes place, send out your press release.

Step 7: Call reporters. When you plan your pitch (the first 15-30 seconds you have to introduce US Against Alzheimer’s and your event or report to a reporter and get them interested), use language that shows how your event/report is unique — is it the biggest, or the first of its kind? For example, “This report is the first to document the growth of Alzheimer’s in [State].” With smaller outlets, a local angle is usually the best lead, as well as any specifics on noteworthy attendees or if a significant crowd is anticipated.

Be sure to respect their time — reporters are usually on deadline towards the end of the day so it is best to call in the morning. Diligent, but respectful, follow-up calls are one of the most important things you can do to get coverage — many reporters are inundated with pitches and releases, and tend to ignore unsolicited emails. Try to speak to the reporter directly (instead of leaving a voicemail).

Step 8: If a reporter is interested, prepare spokespeople for interviews. Interviews can be intimidating for people who have never spoken with reporters on the record before. But with the right research and preparation, there’s nothing to be nervous about. Before entering an interview either for print or broadcast media, be sure to research the reporter’s background and previous stories he or she has written that relate to your issue. It’s also important to understand the audience the reporter is writing for so you can speak to them in your answers. To be prepared for the interview, you must also feel confident speaking on the issue. Before the interview begins, anticipate what questions may be asked and have answers ready, identify potential issues that may arise, know the facts, know what you don’t know, and practice bridging techniques that bring the conversation back to the points you wish to get across in the interview.

Step 9: Things to do in an interview. During an interview, there are many ways you can guide the conversation. During your introductions, set the frame of the conversation by explaining your position and particular areas of expertise. When you begin to tell your story, keep it simple and cite the facts and figures that are relevant in an interesting way. Don’t overwhelm the interviewer or the broadcast audience with too much detail at once, however. Talking about one thing in 10 seconds shows that you are in control; talking about 10 things in 30 seconds is when you risk losing control. Remember that attention spans can be short and reporters like short and easy-to-understand sound bites. Use colorful examples, personal human experiences and real-life comparisons to get your point across. By avoiding jargon, statistics and complex concepts you also keep the interview on track.

Although you do not have control over what questions the reporter asks, you are in control of bridging your answers back to the messages you want to convey. To do this, first acknowledge the question and then bridge to your message. This may sound something like: ‘What may be the case, but one thing to
consider is é òor Ìhatâ not my area of expertise, but I can tell youé òor Ìhatâ an interesting question, it reminds me ofé ò

Step 10: Things NOT to do in an interview. Don't answer hypothetical questions but instead acknowledge that it’s a hypothetical and bridge to a message you want to convey. Don't guess; always be accurate because reporters will check. Don't say “no comment” but either move to another message or, when appropriate, say you’ll have to get back to them with the most accurate findings. Avoid “yes” and “no” answers by seizing the opportunity to tell an interesting story. And lastly, avoid long and complex answers.

Step 11: Helpful interview tricks to remember. If it is a phone interview, consider standing up to sound more energetic. Smile and your message will sound more appealing. When interviewing in person: sit straight in your chair, slightly forward; use your hands effectively by keeping motions between your abdomen and shoulders; and maintain eye contact with the reporter. When a camera is present for a TV interview: speak clearly and not too fast, avoid wearing any clothing that might cause distractions like loud prints and shiny jewelry; and remember that medium-tone blues and grays are recommended color for attire.

Need help or advice?
Email takeaction@usagainstawzheimers.org
General Media Outreach Tips

**Be helpful:** Reporters are busy, so be prepared when you call to help make their job easier. Organize all the information they will need before your first contact. If you’re holding an event, have some materials on hand about USAgainstAlzheimer’s and the issue in case they’d like further information.

**Be specific:** The more specific the information you give reporters the better. If the media knows what to expect they will be able to better cover it. If a prominent figure is working with you, mention this. If you’re holding an event, describe in detail where it will be held.

**Answer “why”:** Why is this newsworthy? This will be a key point for the media, so don’t hide what you are advocating for – state that up front.

**Follow-up — don’t harass:** If you sent a press release and you don’t hear back right away, follow up with a call to see if the outlet received what you sent them or if they need more information. Be diligent but respectful – checking in is one thing, but if you harass reporters they will be less eager to work with you in the future.

**Be polite:** Always remember to thank people – it will go a long way the next time you have an announcement. When in doubt, treat them like a client in a business setting – give them what they need, gently nudge them to follow your lead, and be deferential when they say they have enough information, will get back to you, or cannot follow up on your announcement.

Need help or advice?
Email takeaction@usagainstalzheimers.org
Collecting Signatures for the Stop Alzheimer’s Petition

The Stop Alzheimer’s Petition is a collaborative effort that calls upon policymakers to end Alzheimer’s. Through the Petition, USAgainstAlzheimer’s and the Leaders Engaged on Alzheimer’s Disease (LEAD) coalition are calling on our political leaders to dedicate all resources necessary to prevent and effectively treat Alzheimer’s by 2025. The Petition will succeed with support from Advocates like you, who can collect signatures and help build this movement. Here are some tips on ways to collect signatures.

1. Use Social Media and Email

The internet is a great way to engage your family, friends, and community quickly. You can post about the Petition on your Facebook page and Twitter account, with a link for others to sign and to share the Petition themselves. We also have a tell-a-friend email note that you can pass along to your friends and family. Visit our spread the word page for easy links to share the Petition on social media and by email. If you have a photo or video of yourself to post on social media, those are also effective ways to share the Petition and collect signatures. Remember to include a clear link and mention of the Petition.

2. Collect Signatures in Person

Collect signatures in person at community events, including church, senior’s centers, holiday parties, or sporting events. (You may need to check with organizers first.) You can print paper copies of the Petition. Or bring a laptop computer or iPad to collect petition signatures using the online Petition.

3. Plan Collective Community Action

Host a community-wide Petition drive or competition through organizations you are involved with, including work or school. For example, consider hosting an interdepartmental Petition drive at work. Tie activities to events like National Alzheimer’s Month, the holidays, or community-specific celebrations or festivals.

4. Write a Letter to the Editor or Opinion Piece

Communicate with your local press to educate others about the devastating effects of Alzheimer’s and the Petition initiative. Writing a letter to the editor (LTE) responding to a previous article can be an effective way to communicate your message to the community. An opinion piece (op-ed) is another good way to communicate your message.

5. Ask Community Leaders to Sign the Petition

Contact community leaders (city councilors, state representatives, clergy, prominent businesspeople) and ask them to sign the Petition and share it with their networks. Offer to speak or host a table at events they are organizing or attending, or ask to include a Petition link in their print or electronic communications. Ask community leaders to write their own opinion pieces or accompany you to a meeting with your Member of Congress.

Let us know how you are promoting the Stop Alzheimer’s Petition in your community.

Need help or advice?
Email takeaction@usagainstalzheimers.org
About Us
We Can Stop Alzheimer’s, but Not without You

5.4 million Americans have Alzheimer’s. Their 15 million caregivers are victims as well. The annual cost of Alzheimer’s to America exceeds $200 billion. One in three has family affected by Alzheimer’s. The numbers are staggering. Where is the outrage, where is the outcry?

Who We Are

USAgainstAlzheimer’s is a community of engaged and enraged individuals who have been touched by Alzheimer’s disease and are united by our frustration at a broken status quo. We are dedicated to mobilizing individuals to demand the urgency, passion and commitment needed by our political, business and civic leaders to achieve the goal of ending Alzheimer’s by 2020.

The core of USAgainstAlzheimer’s is family members, caregivers and researchers who have seen the personal toll of Alzheimer’s and understand that the fiscal and societal costs of Alzheimer’s will devastate our nation. We have seen loved ones in the prime of their lives—many as young as 40 or 50 years old—forgetting how to eat and care for their personal hygiene. We have seen mothers with young children caring for their own mothers and fathers, with barely a moment to breathe. And, we have seen people suffer over the course of a decade or longer, slowly losing one brain cell and memory at a time.

Our Theory of Change and a Bold Operating Model

USAgainstAlzheimer’s has a bold attitude and agile operating model. We are disrupting the sluggish ‘business as usual’ pace of Alzheimer’s progress.

Our theory of change is rooted in the strong belief that we, the American people, can create the national will to prevent and treat Alzheimer’s by pressuring our political, business and civic leaders to devote the necessary resources to outcomes-oriented research and to reform the drug development systems that currently slow the development and availability of promising treatments. We call this "leadership for the cure." And it works.

This is how:

- We are demanding an aggressive, transformative federal policy agenda to stop Alzheimer’s by 2020.
- We are building an army of activists whose insistence on a cure is palpable.
- We are providing a continuous stream of simple actions activists can take to advance the movement toward our ultimate goal.
- We are working as a Network of individuals and organizations through new models of collaboration and movement-building.
- We are launching an effort through the LEAD Coalition (Leaders Engaged on Alzheimer’s Disease) to recruit at least one million people to demand that Alzheimer’s be stopped and to call for the successful implementation of the national plan.
- We are educating public officials to recognize the urgency of this quest and the horrible consequences of inaction.
- We are driving innovation through leadership and partnership to accelerate Alzheimer’s prevention, care and cure.
What We Have Accomplished

In two short years, we have achieved the following:

- Successfully persuaded the White House and U.S. Department of Health and Human Services to set a time-based goal to prevent and treat Alzheimer’s by 2025 and create a national plan to achieve that goal.
- Secured appointment as one of twelve non-governmental members of the Advisory Council on Alzheimer’s Research, Care, and Services to advise on improvements to that plan.
- Leveraged personal and political relationships and a strong network of supporters to obtain commitments and proposals for an additional $169 million to fund Alzheimer’s research through the National Institutes of Health and the U.S. Department of Defense.
- Successfully effected the introduction in Congress of legislation specifically aimed at accelerating the development of life-enhancing and lifesaving therapies for Alzheimer’s patients.
- Successfully advocated for the strengthening of Fast Track and Accelerated Review tools for the FDA to use for Alzheimer’s therapies.
- Established an online network of more than 60,000 individuals and the fastest-growing social media presence in the Alzheimer's field.
- Convened Leaders Engaged on Alzheimer’s Disease (LEAD), a coalition of over 50 Alzheimer’s-serving organizations including non-profits and for-profit companies.
- Organized ResearchersAgainstAlzheimer’s to serve as the unified voice for the scientific and research community on the value of additional resources for Alzheimer’s research.
- Helped organize a House Foreign Affairs subcommittee hearing exploring the global burden of Alzheimer’s disease.

Building Networks

We are moving forward with tremendous speed, success and momentum, and we are positioned to be a major catalyst in the effort to end Alzheimer’s disease. To further accelerate our progress and ensure Alzheimer’s receives the national attention it deserves, we are building networks of influencers and activists, initially in five categories: activists, women, researchers, African Americans and Hispanics. Each network includes a target audience, its own unique programming and staff support. In time, we will add other networks of affected groups.

The ActivistsAgainstAlzheimer’s Network builds on the energies of highly motivated Alzheimer’s activists, who are on the front lines of efforts in their communities and nationally. Members of the Network will expand the movement by serving as ambassadors in their communities and bringing others into the fight to end Alzheimer’s.

WomenAgainstAlzheimer’s Network gives voice to women who bear the major burden of the Alzheimer’s crisis and arms women with the information and easy-to-use connections needed to be heard in Washington, in state capitals, and by industry leaders and the research community.

ResearchersAgainstAlzheimer’s increases awareness about Alzheimer’s disease and advocates for more research funding and reforms.

The AfricanAmericanNetworkAgainstAlzheimer’s engages individuals and organizations to be the preeminent voice in and for the African American community on the issue of Alzheimer’s disease and its disparate impact on African Americans.
Hispanics Against Alzheimer’s raises the profile of Alzheimer’s disease and its disparate impact on Hispanics, the most rapidly growing segment of the American electorate.

We believe the power of “US” is in the thousands of researchers, millions of families, caregivers, advocates, hundreds of companies and our public officials.

USAgainstAlzheimer’s (USA2) is a 501(c)(4) organization engaging in public advocacy, federal relations, grassroots activity and voter education.

USAgainstAlzheimer’s Network is a 501(c)(3) organization connecting networks of organizations and individuals to take action to end Alzheimer’s by 2020, while providing the general public, policy leaders and the media with vital information about Alzheimer’s disease.

USA2PAC is an Alzheimer’s-centric political action committee that contributes to the campaigns of candidates supportive of Alzheimer’s issues.

Contact USAgainstAlzheimer’s

USAgainst Alzheimer’s
1101 K Street NW, Suite 400
Washington, DC 20005
Ph: 202.349.3803 Fx: 240.235.5001
ssachar@usagainstalzheimers.org

Learn more at:
usagainstalzheimers.org and usagainstalzheimersnetwork.org
Like us on Facebook: USAgainstAlzheimer’s
Follow us on Twitter: @usagainstalz
Join US in the Fight to Stop Alzheimer’s by 2020

Frequently Asked Questions

What is USAgainstAlzheimer’s?

USAgainstAlzheimer’s is a community of engaged and enraged individuals who have been touched by Alzheimer’s disease and are united by our frustration at a broken status quo. We are dedicated to mobilizing individuals to demand transformative actions to achieve the attainable goal of ending Alzheimer’s by 2020. We are family members, caregivers, and researchers who have seen the personal toll of Alzheimer’s and understand that the fiscal and societal costs of Alzheimer’s will devastate our nation. All of our efforts are based on a rejection of the status quo and a firm belief that hundreds of thousands of voices can—and will—help bring about the end of Alzheimer’s disease as we know it.

What are we up against?

Alzheimer’s disease is the 6th leading cause of death in the United States, and the only disease in the top ten with no disease-modifying treatment or cure. There are currently 5.4 million Americans with Alzheimer’s—a number that is expected to triple in the coming decades. Nearly 15 million Americans serve as unpaid caregivers to loved ones who suffer from the disease and American taxpayers spend $200 billion per year in Medicare and Medicaid related expenses on Alzheimer’s (more than 400 times the amount spent on finding a cure). If substantial progress is not made in stopping Alzheimer’s, Medicare and Medicaid spending will reach $1.1 trillion in today’s dollars by 2050.

How soon can we stop Alzheimer’s?

The research community believes it is possible to stop or control the disease within ten years through disciplined research that is adequately funded. To succeed, we need a political strategy that ensures that elected officials and policymakers make fighting Alzheimer’s a national priority and enact a clear plan for a cure.

How is USAgainstAlzheimer’s building advocacy networks to fight this disease?

USAgainstAlzheimer’s strategy to defeat Alzheimer’s by 2020 is bold and comprehensive. The heart of our inclusive effort is a ground-up mobilized effort to demand change. We know that engaged activists are a crucial part of movement-building, and we are committed to supporting people-powered social change.

USAgainstAlzheimer’s is about the millions of Americans who quietly and anonymously suffer from Alzheimer’s. It is about the caretakers who work around the clock and witness up close Alzheimer’s painful toll on their loved ones. It is about the researchers tirelessly working to find a cure but who desperately need greater resources. It is about all of us, who despite our pain, despite our anger, and despite our heavy hearts know with certainty that we will live to see a day when Alzheimer’s is defeated.

Our movement is a disruptive one fueled by passion and the belief that the current lack of focus on the issue is not acceptable and must be changed. We work to raise awareness about the Alzheimer’s crisis among policymakers, candidates, and the general public. We partner with health, science, and community organizations to expand our political influence. We go to Congress and educate members on the crisis and strategies that can defeat the disease.

Together, we will spur innovations in science, industry practice and regulatory processes essential to the discovery of safe and effective therapies needed to stop Alzheimer’s.