

**THE ARC OF ALZHEIMER'S: FROM PREVENTING
COGNITIVE DECLINE IN AMERICANS TO
ASSURING QUALITY CARE FOR THOSE
LIVING WITH THE DISEASE**

HEARING
BEFORE THE
SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE
ONE HUNDRED FIFTEENTH CONGRESS

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WEDNESDAY, MARCH 29, 2017

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The Committee met, pursuant to notice, at 2:36 p.m., in Room SD-106, Dirksen Senate Office Building, Hon. Susan M. Collins, Chairman of the Committee, presiding.

Present: Senators Collins, Tillis, Fischer, Casey, Gillibrand, Blumenthal, Donnelly, Warren, and Cortez Masto.

**OPENING STATEMENT OF SENATOR SUSAN M. COLLINS,
CHAIRMAN**

The CHAIRMAN. This hearing will come to order.

First of all, thank you all for that wonderful welcome, which I know was for Maria Shriver, but—

[Laughter.]

The CHAIRMAN. But we Senators will pretend that it was also for us.

[Applause.]

The CHAIRMAN. Good afternoon to all of you. I am delighted to convene this annual hearing to assess the arc of Alzheimer's, from preventing cognitive decline to assuring quality care for those living with dementia. It is always so inspiring to sit here and look out at that sea of purple. But it is also a reminder that this terrible disease has affected each and every one of you in a personal way.

Over the years, I have met family members who have sacrificed so much to care for their loved ones living with this disease. I have met Americans living with Alzheimer's with courage and determination. Many of you are here today, and we welcome you.

Two years ago, I met Bob O'Keefe from Waterboro, Maine. Alzheimer's ran in Bob's family. His father and older brother both had it, so Bob decided to get tested early. He received his diagnosis in 2009, and immediately he became a fighter. He walks daily and reads a couple of books a week. He organizes support groups in his small rural community. He told me, "There are days that are overwhelming. But," he stressed, "never quit. Every day is a new day."

Today we should ask, What can we do to help people like Bob? Given our rapidly aging population, we cannot afford to do nothing. Alzheimer's is a devastating disease that exacts a tremendous per-

sonal and economic toll on individuals, families, and our health care system. Approximately 5.5 million Americans are living with the disease, including 27,000 in my State of Maine. That number is soaring as our overall population grows older and lives longer. If current trends continue, Alzheimer's could affect as many as 14 million Americans by the year 2050.

In addition to the human suffering it costs, Alzheimer's is our Nation's costliest disease. The United States spends more than \$259 billion per year, including \$175 billion in costs to the Medicare and Medicaid programs. It is the only one of our Nation's most deadly diseases without an effective means of prevention, treatment, or a cure. If we do nothing, the Alzheimer's Association forecasts that this disease will cost our country an astonishing \$1.1 trillion by 2050, and it will bankrupt the Medicaid and Medicare programs.

Now, the good news is that we are making progress. In 2011, the National Alzheimer's Project Act, known as "NAPA," which I co-authored with then Senator Evan Bayh, became law. It created a national plan to combat Alzheimer's that is updated annually. NAPA focuses our efforts to accelerate progress toward better treatments and means of prevention and ultimately a cure.

In the biomedical world of research, we are also making progress. Scientists are conducting prevention clinical trials that never would have been possible even a few years ago. And I have had the great privilege of visiting with some of the research scientists who are on the cutting edge of doing clinical trials and laboratory work, and it is exciting.

In fact, Senator Casey, I went to the University of Pennsylvania which is doing tremendous work, and I am proud of the work that Jackson Laboratories in my State is doing, and Harvard, and the list goes on and on.

Today through advances in imaging technologies, we are able to identify some of those who are most at risk for Alzheimer's and test interventions before symptoms develop.

Although we do not yet know how to prevent Alzheimer's, we are advancing in our understanding of the disease. Its progression does not happen overnight. It is preceded by years and perhaps even decades of changes in the brain and a continuum of changes in behavior, including cognitive decline.

A growing body of evidence even suggests that lifestyle factors could decrease the risk of cognitive decline. Today we will learn about the state of the research on factors such as cardiovascular risk, physical activity, diet, sleep, social engagement, and cognitive training. If we start today, a public health approach to improve brain health may well be possible.

For those living with the disease today, and given the rising projections for the future, we need to ask: Are we equipped to provide the best care across various settings, from homes to hospitals? We know that the number of geriatricians falls short of the growing demand. We know that for those living in rural areas, such as in my State, that respite care is far too scarce. We will discuss innovative approaches to delivering dementia training to help care providers across the spectrum, from primary care physicians and nurses to

social workers and community health workers, and family caregivers are especially important as part of this picture.

Last year, more than 15 million Americans provided 18 billion hours of unpaid care to family members and friends with Alzheimer's disease. This is valued at more than \$230 billion. We will shine a light on how to better support these efforts.

When I look at the arc of Alzheimer's, I recognize both the progress we have made and how far we still have to go. We have come a long ways in advancing research through more robust funding. Last Congress, we increased funding for Alzheimer's research by 60 percent to almost \$1 billion. The fiscal year 2017 appropriations bill, as reported by the Appropriations Committee on which I serve, would take us to nearly \$1.4 billion.

Now, why are those figures important? Well, the experts have calculated that we need to invest \$2 billion a year in research funding to achieve our goals.

We certainly cannot afford to go backwards at a time of such great urgency and progress, and that is why I so strongly oppose the administration's plan to slash funding for the National Institutes of Health. That is the last thing we should do.

[Applause.]

The CHAIRMAN. I want to thank all of our witnesses for joining us today, and I especially want to thank each and every one of you who have traveled from your home States to be with us. Some of you remember from last year that I wore this same purple suit because it is the color that we are all using today. This suit is like 15 years old, and I really want to retire it. But I have made this pledge that until we have an effective treatment, this suit stays in my closet.

[Applause.]

The CHAIRMAN. Senator Casey, I am delighted to recognize you for your opening statement.

**OPENING STATEMENT OF SENATOR ROBERT P. CASEY, JR.,
RANKING MEMBER**

Senator CASEY. Chairman Collins, thank you very much, and thank you for saying some things that elicited applause. That does not happen very much in hearings.

[Laughter.]

Senator CASEY. So we are grateful. But I do want to thank you for calling this hearing and for your dedication on this issue. It is a topic that I think touches everyone in this room in one way or another, some more directly, obviously, when it is a family member. But whether it is a parent or a grandparent, a sibling or a friend, or even a neighbor, you know what this fight is all about.

Our witnesses, who are in that fight as well, come to us today from all across the country. A little bit later I will have an opportunity to introduce Phyllis Gallagher from Frackville, Pennsylvania, not far from my home town of Scranton, and we appreciate her being here today. Phyllis cares for her husband, John, who began showing signs of early onset Alzheimer's at the age of just 49, and we are grateful that she is willing to do that today to provide that testimony.

It is also an honor, of course, to have Maria Shriver here with us today to help raise awareness about the issues that families across our country face in families like hers and like the Gallagher family.

Alzheimer's disease severely impacts both the lives of those who are diagnosed with it and the lives of those who care for them. Just consider this: Just in one State, Pennsylvania, 270,000 people ages 65 and older currently live with Alzheimer's. Providing much of the care for these individuals is an enormous but often unseen army of caregivers, including friends, family, and neighbors, just as Senator Collins alluded to earlier. In my home State of Pennsylvania, an estimated 673,000 people provided unpaid care to a person with Alzheimer's-related dementia in 2016 alone. So 270,000 people living with Alzheimer's, 673,000 providing assistance. So those numbers will only grow, not only in a State like ours but in States across the country.

So that is why we are here today, to talk about how we can slow down this disease and ensure that those who develop the disease itself receive the best medical care and the best support possible. Scientific research is providing us with new insights into how we can better control the impacts of Alzheimer's disease.

For example, we are discovering that physical activity can prepare our brains to fight back against Alzheimer's and to potentially delay the onset of symptoms. Increasingly, we are hearing the experts tell us, "What is good for your heart is good for your brain." We must continue to support research in the quest for interventions that can help us prevent the onset of the disease and one day develop the cure.

Until that time, we must focus on making sure that those who are already living with the disease can get the best care possible. This requires that we have a health care workforce properly trained to address the unique needs of individuals with dementia. This must include care providers across a continuum of care, from primary care providers to nurse practitioners to, of course, direct care workers.

We must also increase the number of doctors specializing in health issues that affect older Americans more broadly. Someone living in an apartment building in Philadelphia or on a farm in Washington County, Pennsylvania, must both have access to care when they need it. All of this will not be enough, though, if we do not also engage the largest component of our caregiving workforce—our family caregivers, as Senator Collins reminded us. Caring for a loved one is emotionally, physically, and financially draining. We know that. We also know that family caregivers require our support and need to be provided with the resources they need to properly care for both their loved ones and themselves.

As the experts tell us, we have made progress in all of these areas: research, workforce, and caregiving. But our work is far from over, and in some cases, it is just beginning. We know, as Senator Collins just told us, funding is critical, and I join her in that disagreement, I will add even denunciation or condemnation, of any budget proposal that cuts NIH the way that the budget proposal does. For too long—

[Applause.]

Senator CASEY. For too long, we have not made progress on funding. Last year, we had a breakthrough. Our great bipartisan moment—which guaranteed it did not get a lot of coverage but it was a great moment.

[Laughter.]

Senator CASEY. And at that time, we moved in the right direction in terms of funding NIH. This budget idea would be—or proposal, I should say, would be a giant step backward, or more than one step.

So I am pleased to join her in that effort, and I am also committed to helping us get to the point where we are getting closer and closer to the \$2 billion funding targets that experts tell us that we need.

Over the past several years, with the help of so many people in this room, we have made real progress in funding, but we have got a long way to go.

Let me just wrap up with this one message. In addition to focusing on these priorities, we have got to make sure that this stays in front of the American people on a regular basis and the leaders here in the Senate and the House. We cannot look at the faces in this audience, people who have come here year after year, and the pain and the heartache that so many have suffered with regard to this terrible disease and not insist that more has to be done. We need to keep investing in science, keep supporting clinical trials, and keep supporting families. That is why this gathering today is so essential for patients and for families.

Let me just conclude as well with a reference to two programs that I think are critical to this: Medicaid and Medicare. We had an effort that was undertaken most recently which, in my judgment, would have hurt Medicaid terribly. We have to make sure that we stop efforts that are headed in that direction. We have got to step up the fight against Alzheimer's, if anything, increase the pace and the intensity that we bring to this issue.

I am grateful that you are all here on this day. We are grateful for your continuing commitment, and I am grateful for the witnesses' testimony, as well as our Chair getting us together today.

Thank you, Chairman Collins.

[Applause.]

The CHAIRMAN. Thank you very much.

I want to acknowledge the presence of many of my colleagues who are here today: Senator Fischer, Senator Tillis, Senator Gillibrand, and I know Senator Warren is going to be back as well. And I suspect we will be joined by others.

I am now delighted to introduce our first witness, Maria Shriver. Ms. Shriver is a journalist and the founder of the Women's Alzheimer's Movement. Ms. Shriver is a champion in fighting Alzheimer's disease. She founded the Women's Alzheimer's Movement to advance research and to find out why two out of three brains that develop this disease belong to women. She has kicked off the Move for Minds, a partnership to raise money for research and raise awareness about lifestyle changes that one can make to promote brain health.

Ms. Shriver, I so remember your previous testimony here. In 2009, you testified so poignantly about the story of your father, and

I will never forget you telling me that when he could no longer remember the names of his loved ones, he could still recite the “Hail Mary.” And that was just such a poignant moment in your testimony.

I also want to acknowledge that your daughter Christina is here today, and we are delighted to have her as well.

Thank you for all your work, and please proceed with your testimony.

**STATEMENT OF MARIA SHRIVER, MOTHER, JOURNALIST, AND
FOUNDER OF THE WOMEN’S ALZHEIMER’S MOVEMENT, LOS
ANGELES, CALIFORNIA**

Ms. SHRIVER. Well, good afternoon, and thank you, Chairman Collins, Ranking Member Casey, and members of the Committee for inviting me here today. It is an honor to be here with so many extraordinary people. Every single person behind me could actually be testifying and tell an incredible story, so I am honored to be here speaking on behalf of all of these incredible people.

As Chairman Collins mentioned and as some of you may know, I have been here before, 8 years ago, to be exact. In March of 2009, I sat here and testified about how Alzheimer’s had taken up residence in what had been my father’s beautiful brain.

My father, Sargent Shriver, was an idealistic, intelligent, optimistic, and dedicated public servant. His mind was as sharp as they come—a beautifully tuned instrument that left people in awe and inspired. He was an expert at sharing his passions with the general public, with thought leaders, and with people like yourself. He often came here to the Hill to advocate for increased funding for his beloved Peace Corps and all the War On Poverty programs that he created, including Head Start, Vista, Job Corps, and Legal Services for the Poor.

He loved working this building, and he was really good at it. He knew every Senator and Congressman by name. And if he were here today, he would know every single thing about each and every one of you—about your careers, about your interests, your politics, your families, and, yes, your soft spots. He would know a lot about that.

So imagine how painful it was to watch when this walking encyclopedia of a man went from knowing every fact about everything that had ever happened in the history of this country to not knowing what a spoon or a fork was, to not knowing what my name was, or not knowing his own name.

Two years after I testified, my father died of Alzheimer’s disease, and now I am back—back again to testify, back again to sound a 911 alarm about the biggest biomedical crisis facing the world today—and I say that it is a world crisis—back again to focus your brains on this killer ravaging brains and families across this great country of ours.

Believe me, I wish I did not have to come back here to testify. It was not on my calendar. But when I learned that the funding for NIH and Alzheimer’s research might be in jeopardy, I practically ran here to say, “This just cannot be. Wait a minute. There must be some mistake here.”

I know that this Committee is well aware of this crisis unfolding in homes across this country. I know you know about it firsthand, and I know you know about it from the people that you represent. But let me use this moment to remind you here on the Committee and the American public just what the up-to-date facts really are. And trust me, these are real facts.

Every 66 seconds, another brain will develop Alzheimer's disease, and two-thirds of those brains belong to women—two-thirds of them—and no one knows why that is. A woman in her early 60s is twice as likely to get Alzheimer's in her lifetime than she is to get breast cancer. And the statistics are even more alarming for women of color. African American women are twice as likely to develop Alzheimer's as Caucasian women, and Latinas one and one-half times more likely.

On top of that, more than 15 million Americans are caring for someone with Alzheimer's or other forms of dementia while they are also parenting and holding down full-time jobs. And just so you know, two-thirds of those caregivers are also women.

All of that is why I founded the Women's Alzheimer's Movement—to educate all of us about the disproportionate effects of this disease on women. I believe that determining why women are more affected by Alzheimer's will help us unlock some of the mysteries of this disease.

Instead of focusing only on the formation of plaques and tangles in the brain, let us also start focusing on women's brains and on their bodies—on their chromosomes, on their hormones, and on the way they process inflammation. This could help us learn more about Alzheimer's progression and about its prevention.

In fact, I believe studying women and getting more women into clinical trials could possibly lead to the cure for all of us. I do not believe that this is sexist. I believe it is just plain old smart. It is smart—thank you.

[Applause.]

Ms. SHRIVER. It is smart because Alzheimer's is the most complex, mysterious, and expensive disease in the United States, more expensive than heart disease and cancer, and it is the only one of the top ten diseases without a means to prevent, cure, or slow its progress.

In fact, since 2000, the number of deaths from breast cancer, prostate cancer, heart disease, and stroke are all down. But Alzheimer's deaths are up—up by a breathtaking 89 percent. It is bankrupting families, and it is on its way to bankrupting this country.

This year, if you add families' out-of-pocket expenses to the money Medicare and Medicaid will be spending on Alzheimer's, the projected total will drain the economy of \$259 billion. And if our Government does nothing, the costs are projected to explode to an astounding \$1.1 trillion. I hope we can sit for a minute with those incredible, astounding figures.

I want to take a moment to thank you, Chairman Collins, for introducing a bipartisan resolution declaring that achieving the primary goal of the National Plan to prevent and effectively treat Alzheimer's disease by 2025 is indeed an urgent—and I say “urgent”—national priority because right now it is the most seriously under-

funded disease in our country, this at a time when every Alzheimer's scientist will tell you that we are at a critical and potentially groundbreaking moment in the history of the research of this disease. So much extraordinary progress has been made, but now it is stalled. The only thing many of them say keeping us from pressing on to find a cure is the Federal funding to move us forward.

For instance, my friend Dr. Rudy Tanzi at Harvard, one of the scientists that the Women's Alzheimer's Fund actually funds, is a top Alzheimer's researcher who discovered the first gene for the disease 35 years ago, and his lab has found two dozen more in the last decade. He says that we have learned from studying these genes important clues about what needs to be done to prevent Alzheimer's a decade or so before any symptoms arise. But he says laboratory budget constraints mean researchers like him are able to follow up now only on about 10 percent of the new clues and information that is available, and that is just one lab.

The United States Government is better than this. We are letting down the millions who have this disease, the millions who are caring for them 24/7—and it is a 24/7 job—and the millions who are going to get Alzheimer's disease and other forms of dementia as we, the baby boomers, and our millennial kids continue to grow older.

Right now, 10,000 people are turning 65 every day. Remember I said that a brain develops Alzheimer's every 66 seconds? Well, by 2050 someone in the United States will develop Alzheimer's every 33 seconds. Every 33 seconds.

We have to fund this disease at the level it deserves before it levels all of us and our health care system.

[Applause.]

Ms. SHRIVER. We have to fund it at the level we funded AIDS and that we funded cancer. This is an equal opportunity crisis, a tsunami that can crash into any and all of us, Republicans, Democrats, Independents. And make no mistake: without a Federal commitment like you have spoken about, we are going to lose this fight.

You know, over the years I have racked my own brain wondering why Alzheimer's does not get funded at the level of these other diseases. I have asked myself, is it not being marketed properly? Is it not sexy enough, hip enough? I have wondered, is it because we think it is just a normal part of aging? Which, of course, it is not. Or is it because our country is so obsessed with youth and none of us want to grow old?

Then I thought to myself, maybe it is sexism. Maybe because it disproportionately affects women, that is why it is not getting funded. I cannot tell you how many people, even doctors, have said, "Well, isn't it just because women live longer?" No, that is not why women are getting it.

"So what is it?" I have thought to myself. Is it because deep in our hearts we are all so terrified of losing our own minds that we just want to push this disease out of the field of vision, we are trying to deny that it even exists at all?

Well, the truth is we cannot deny it away anymore. Alzheimer's is everywhere, and it can develop in your brain for 20 years before

a single symptom ever shows up telling you that you have it. And what does that mean? It means that the chances are that several of us sitting in this room right here today have it right now, and we do not even know it. Think about that for just a minute. Imagine one of you up there, imagine one day turning to someone that you have served with in this August body for years, and not knowing who they are. Imagine looking at the person in your home who you have loved for decades and you cannot remember their name. Imagine your family being unable to care for you physically, financially, emotionally, or spiritually. Imagine. Imagine that scenario.

Well, millions of Americans do not have to imagine it. Probably most of the people in this room do not have to imagine it because they are actually living it.

One of them that I asked to join me here today in this room is 61-year-old Pam Montana. She is right there. She is sitting behind me. I wanted her to come here today because she was just diagnosed with Alzheimer's. Her diagnosis forced her to leave a successful career at Intel, and it forced her husband, Bob, to quit his career as well so he could care for her. They face an uncertain future, and a scary one at that, but I wanted you to see Pam because she is the face of Alzheimer's, a woman in her prime, a mother, a wife, someone who had a successful career, who was earning money. This is the face of Alzheimer's. And she and her husband, along with all of the people in this room, have come here to Capitol Hill from all over this country to use their voices to advocate for increased funding, to tell you what it is like to live like this every single day 24 hours a day.

You know, there are so many brilliant minds now focused on this issue, so many forceful advocates like those of you on this panel and the 1,300 Alzheimer's Association advocates that are fanning out across the Hill today. So many ones like the ones in this room who can no longer accept when they are told, "We just do not know what causes this disease or what to do about it." For them, that is plain old unacceptable. And for me, as a child of Alzheimer's, it is also unacceptable. And as someone who is Pam's age, it is terrifying.

The statement "We just do not know" needs to be repealed and replaced. It needs to be repealed and replaced with this: "We do know, and here is what you can do." Because it was not so long ago that HIV/AIDS was a certain death sentence and cancer pretty much was incurable and now so many of them are curable. Science and investment in science has turned all of that around. But nobody—nobody—who has ever been diagnosed with Alzheimer's has ever survived it. We can and we will do better than that.

You know, when my uncle John F. Kennedy was President, he challenged this country to put a man on the moon. It had never been done before. Well, today I challenge you to also do something that has never been done before. Give us the first person who survives a diagnosis of Alzheimer's disease.

I am asking this—

[Applause.]

Ms. SHRIVER. I am asking this Congress to do what it takes to get our brilliant researchers back up and working at full capacity in their laboratories around this country, doing what they do best,

which is finding solutions, finding answers, finding cures. And not only that, until we find a cure, we have to do a better job, as you have talked about today, educating the public on ways to live healthier lifestyles.

We now know through science and technology that the brain never stops developing. Believe it or not, that is new. So we need to educate people on the connection between brain health and healthy diet, physical activity, and stress reduction, and how they can expand their brain power with lifelong learning and social connection. This is a priority for the Women's Alzheimer's Movement, which is why we have partnered with the Equinox sports clubs and gyms all across this country for a national program called "Move for Minds." We are determined to get this message out to mainstream America that they can control their brain health, that their genes are not their destiny.

We also need to get support to the millions of caregivers. We have spoken about them today. The ongoing stress on these families is unimaginable. They need the resources to help them care for their loved ones while also working. And we must also ensure that there is a well-trained professional workforce ready to provide quality care to the increasing number of people living with Alzheimer's and other dementias and who will need their services at home and in facilities as they grow older.

I know you might be thinking that this is quite a to-do list, but I have never met anybody—I have never met a woman who was not good at crossing off her to-do list. And I strongly believe that this to-do list is something we can actually do. Even in this current climate, and perhaps more so in this current climate, the American public is desperate to see Democrats and Republicans work together. They are desperate to see success here in Washington. And this is a great place to start.

So I am asking all of you, with the brains that you do have today, to come together, Democrats and Republicans, and make a commitment. Let us do what we need to do to stop the onslaught of this mind-blowing disease, because America should be the leader in solving this global medical crisis. We are the greatest country on the planet, and finding a cure for this disease will make us the smartest one to boot.

Thank you very much.

[Applause.]

The CHAIRMAN. Thank you so much. Thank you. Thank you.

[Applause continues.]

Ms. SHRIVER. Do not make me cry.

The CHAIRMAN. Thank you so much for your very compelling testimony. As you can see from the response that you have received, I think you have motivated every single person who is here as an advocate to go to their Senators and House Members and tell the story of what is needed and that we certainly cannot stop now. We have to continue to go forward, and that does require funding. And if ever there were a case where investment is going to pay dividends and ultimately not only save money but improve the quality of people's lives, it is an investment in Alzheimer's disease. So thank you.

[Applause.]

Ms. SHRIVER. Absolutely, and this will indeed make America great again.

[Laughter.]

Ms. SHRIVER. Because this is, as we have said, the most expensive disease in the country right now.

The CHAIRMAN. It is.

Ms. SHRIVER. So funding it and finding ways to prevent it and/or cure it will save us billions of dollars.

The CHAIRMAN. You raised a very interesting point about why people are less comfortable with talking about Alzheimer's disease, and you told the Committee back in 2009, when your Dad had been diagnosed 6 years earlier, that you had felt at the time confused, powerless, and alone. I think a lot of people still feel that way when they get the diagnosis or when their loved one does.

Do you feel there is a way that we can reach out more to families who are dealing with this devastating disease?

Ms. SHRIVER. Well, yes, and I think that all of the people in this room feel very hopeful. They are putting their hopes in this Committee, they are putting their hopes in their Government, that you will actually secure the funding to find a cure for this disease.

I think the more we talk about subjects that are somewhat taboo, the more we talk about aging, what it is really like, the strength it really takes to age, the more we talk about the truth about caregiving, how complicated and difficult that is, the more we try to engage not only just lawmakers but corporate America, the more we try to get companies to look at caregiving leave, the more we try to encourage them to keep people working who are boomers, the more we really talk about the reality of how our country is aging and the needs of our population, I think this disease will lose its stigma. And people, I think, do not want to talk about it because they are afraid of losing their jobs; they are afraid there is not a cure; they are afraid if they tell somebody or even if they get tested, what hope is there for them? Which is why we are often talking so much about the lifestyle choices now that we are making. What we are learning is that, as I said, our genes are not our destiny. We are now learning that there are things we can do to keep our brains engaged, things that 20-, 30-, 40-year-olds need to start doing.

We are now learning about the benefits of interval exercise, of certain kinds of food, of meditation, of, you know, how we manage stress, and there is nothing more stressful than trying to manage a job, be a parent, be a provider, and be a caregiver. So I think the more that people out in Main Street America see their elected leaders acknowledging that funding needs to happen for this disease, that support needs to happen for the caregivers, that the more they see success here, the more hopeful they will be out there.

The CHAIRMAN. I think that is exactly right.

[Applause.]

The CHAIRMAN. I also believe that people, when they are first diagnosed, are worried they are going to be isolated and treated differently by their family and friends because of the stigma to which you referred.

I want to switch to another topic in just the less than 2 minutes I have left. I know that you have kicked off the program Move for Minds, and you alluded to it in your testimony. And this is fascinating because we are going to hear from our next panel about some of the interesting research that suggests that, in addition to the genes that may produce Alzheimer's, particularly early onset, there are ways that we can stave off or delay the disease for some people—not for everyone.

Could you talk more about what you have learned about the body-mind connection? You were starting to talk about that.

Ms. SHRIVER. Well, amazingly, people are surprised that they are connected, which is so extraordinary. This is one body, and our brains and our bodies are connected. And Senator Casey was mentioning that we are now learning that a heart-healthy diet is also good for the mind. We are learning that. We are learning, as I said, that the mind can continue to grow. It is important to learn new things. Just because you learned certain things up until you were 30 or 40 does not mean you do not have to keep engaging the mind. And through technology, we have been able to study the brain and see how it can continue to grow.

A piece I am doing for NBC this week is on the super-ager brain, and there are now studies of people who are in their 70s and 80s who have a brain of a 20-year-old. And it is really interesting. They are people who push through, who are constantly learning, and when it is hard to learn, they push out of their comfort zones. They are also people who manage stress differently than a lot of other people.

So we are beginning to learn things about how the brain ages, and I think one of the things certainly that Move for Minds is advocating is a holistic approach, learning, staying socially engaged, exercise. Every researcher and doctor that I have spoken to as I have traveled this country and I say to them, "If there is one thing I could tell people to do, what would it be?" And they say, "Exercise, exercise, exercise, because that pushes the blood to the brain."

So eating a mind- or brain-healthy diet, exercising, learning new things, challenging yourself, pushing yourself out of the comfort zone, eating properly, meditation, mindfulness, turning off technology, resting your brain, sleeping—these are all lifestyle things that we are now learning affect not just the body but the brain, and that we can start doing them when people are very young. As I have said, Alzheimer's manifesting 20 years in your brain, this is something that we are—a message we want to get out to 30-, 40- and 50-year-olds, and particularly also to women who are perimenopausal or menopausal. That is why I am excited about a lot of the research that we can perhaps get going on women, because we are different and women are handling these lifestyle issues differently than men. And that really has not been looked at.

The CHAIRMAN. Thank you very much.
Senator Casey?

Senator CASEY. Thanks very much, Madam Chair.

Ms. Shriver, we are grateful you are here again. We wish you did not have to come back because we want to make more progress on this challenge, but I thought one of the best things, among the

many things you said that were inspiring, was we hope that down the road we are going to be able to say, "Here is what you can do," as opposed to something else. So we are grateful that you brought that sentiment and that goal to us here in the Senate. And it is a mission. This is, I think, a mission worthy of a great country, and you have given us a good road map and a good to-do list. We are grateful for that.

I wanted to focus on a program that I think we are all more—not just aware of now, but I think a program that we appreciate more than we did even a few weeks ago or a few months ago, and that is Medicaid. Among the many things that Medicaid does, for example, it provides health care for 1.1 million children in my home State. Lots of folks get into nursing homes because of Medicaid. And a third major category, of course, are Americans with disabilities. Your family has done so much, it is hard to calculate the impact your family has had in a positive way on people with disabilities.

We are told that one segment of the disability community, those with Down syndrome, those Americans are disproportionately impacted by Alzheimer's. And I wanted to ask you what would you hope we could do about that, and if you have yet another to-do list, we would love to have it.

Ms. SHRIVER. Well, my brother Timothy, who runs the Special Olympics, would probably best be equipped to deal with that, but certainly the statistics do show that people with Down syndrome, 100 percent of them do end up with Alzheimer's. But only 50 percent of them actually exhibit the traits. So I think there are some interesting studies going on. Some families have very bravely volunteered to be in those trials and in those studies.

I think one of the things we are trying to do is to get more Americans, be they families with Down syndrome or just, you know, women and men in particular, into these clinical trials. I have talked to researchers all across the country; they say they have a really difficult time getting people to participate in clinical trials. And so this is a big mission of mine, to actually ask people, also to ask corporate America to make it easier for people who work for them to participate in clinical trials. Now if you participate, you have to take vacation time or a sick day. What about the idea that they would pay you? You know, you do not have to take time off to actually participate in a clinical trial because it is a form of national service. We all benefit from individuals brave enough who take the time to participate in clinical trials.

So once again, this comes back to funding, this comes back to making it possible for families to participate in trials, be it a family with a Down syndrome member, and there is also, you know, a lot of fear that goes into that. Obviously, people participating in those trials, I think people are generally afraid to participate in a trial. But I have also met other ones who say that knowledge is power and that they know more people who would participate if it was easier to participate.

Senator CASEY. I appreciate that. Finally, I just wanted to thank you for highlighting the disproportionate impact this disease has on women. I grew up with four sisters and have four daughters.

Ms. SHRIVER. Whoa.

Senator CASEY. So this is especially—

Ms. SHRIVER. How are you?

[Laughter.]

Senator CASEY. Doing just fine.

Ms. SHRIVER. There is a book in there somewhere.

Senator CASEY. But we are grateful, and I just hope we can—and this is a challenge that you pointed to and I think all of us wrestle with. It is not just the focus on funding, but sustaining that focus over time.

Ms. SHRIVER. Right.

Senator CASEY. Because like a lot of things in the Senate and the House, and I guess society more generally, we go from one issue to the next. And what is a front-burner major issue on a Monday afternoon can be forgotten about even by Tuesday morning. We have to figure out more and better ways, I think, to sustain the focus on the urgency, the primacy of getting more funding. And I am grateful that you gave us the inspiration today to do that and also the data that undergirds that urgent priority.

Ms. SHRIVER. Thank you, Senator. And I think what is particularly alarming to me is that most women do not know that they are at risk. They do not know these facts. They do not know that there are things they might be able to do today that could perhaps prevent this or delay. And they do not know that there are things that they could begin to do in their daily lives that might help them out.

But I also think that more and more advocates like the ones in this room are going to tie their votes to people who support this kind of funding. They are getting really smart about advocating and making sure that their voices are heard. And I encourage them to do that because this needs to be a front-burner issue every single day, not just for the people in this room—for many, it is too late for them—but for the millions, as I said, turning 65 every single day, the baby-boomer generation, and our children. Because if I were to get Alzheimer's, it is going to impact my entire family. It is going to impact the future of my children's work life. It is going to impact their parenting, how their families unfold. And I happen to be able to afford care. Millions and millions of Americans cannot handle the out-of-pocket expenses that they are incurring today. It is putting them into poverty on the brink. They are quitting their jobs. They are mortgaging their homes. And it is excruciating.

So this is a front-burner issue if I have ever seen one, and I have been around politics a long time. This impacts the entire family, and it is impacting at a level that we have never seen before.

Senator CASEY. Thank you very much.

Ms. SHRIVER. Thank you.

The CHAIRMAN. Thank you.

Senator Fischer?

Senator FISCHER. Thank you, Chairman Collins and Ranking Member Casey, for convening this important hearing today, and I also want to thank Ms. Shriver and all of our witnesses for being here. I am very pleased to join the Aging Committee this year.

The impact of Alzheimer's is felt far beyond just those who are afflicted with this really evil disease. It is felt by family and friends, caregivers and others who interact with these individuals.

Every family has a story. My sister-in-law is a victim of early-onset Alzheimer's, so I am thankful that we are having the hearing today on this topic.

Ms. Shriver, through your work across our country, what are some of the memorable and innovative, really local or community-based approaches that you have learned about or that you have seen, and maybe that you have even helped to develop, that will help the victims and help contribute to this fight we have against this disease?

Ms. SHRIVER. Thank you, and I am sorry for the pain in your own family, and thank you for sharing that. One of the big things that I am always in awe of is that families do share their stories because it takes great bravery to share your stories, and that is how we get these stories more out into the public arena, and it is how we begin to destigmatize this disease.

When I was First Lady of California, I came into contact with several different kinds of daycare centers where working women could bring their children and their parents simultaneously, and it was really quite inspiring to see kids who were about 5 or 6 read stories to people who were grandparents. This was, I think, an innovative approach because you did not have to go to two or three different locations to drop a loved one off.

One of the great challenges I found when my Dad got Alzheimer's and my mother began to get strokes was finding caregivers in the professional workforce who were well trained about the differences in these brain-related challenges, someone who has a stroke versus someone who has Alzheimer's or Parkinson's or another form of dementia. We need a more educated workforce, and obviously a caregiving force that makes a living wage as well.

But I think there are a lot of innovative, you know, facilities going on, people who are using music and art and different kinds of therapy to engage the mind. What we are learning is that music engages parts of the brain. As Senator Collins said, my father did not know who I was, but he could say a "Hail Mary" and he could sing a song that he knew when he was 18.

So there is still so much we do not know about the brain. I think we have to look at, just as we look at parental leave, maternity leave, elder care leave, caregiving leave, look at different kinds of forms of daycare, elder care, child care, how we can combine that in different locations, because we often find that those with Alzheimer's at later stages are doing a lot of the same activities that little children can do, also looking at more intergenerational living systems. I think I was very excited—I have seen homes where young kids went to live—they were going to college, and they lived rent-free in a building which was mainly seniors with Alzheimer's, and in exchange for room and board, they played music or they went and had meals with people with Alzheimer's and how that benefited more generational living. I think that is an exciting new space. So whether it is in terms of daycare and elder care combined, whether it is terms of, you know, young people, millennials living alongside people who are 70 and 80 years of age, I think that is an exciting, new, and inspiring way for the future.

Senator FISCHER. And I know since you were last here, we have seen some amazing strides in research and the development that

we have there. We have looked at education and prevention and treatment also.

What do you see as the most significant milestones that we have reached so far? And what do you envision as being achievable?

Ms. SHRIVER. Well, I envision a cure being achievable immediately. I envision a cure. I envision, you know, some pill or like what happened with AIDS, where you can get this diagnosis but continue to work and live and be a productive member of society. I really do believe that if the Federal funding reaches the level that we have asked for or beyond that, a cure is within our reach. As I said, it happened for AIDS activists. It happened in the cancer field. And I see no reason why it cannot happen in the Alzheimer's space as well.

I think this is a very complex and mysterious disease. I think it is—every researcher that I have talked to says it is really—we have to actually approach it perhaps differently than we have been approaching it in the past. We have to look at people earlier. We have to look at women versus men. We have to look at chromosomes. We have to look at inflammation. We have to look at things that perhaps we did not look at before, focusing more on plaques and tangles.

But I am really hopeful, really hopeful, that a cure is within our grasp. And I do not mean 20 years from now. I mean 5 or 10 years from now.

Senator FISCHER. Thank you.

Thank you, Madam Chair.

The CHAIRMAN. Thank you.

Senator Tillis?

[Applause.]

Ms. SHRIVER. But I would just add that I am going to be back here again if we do not get the funding and we do not get a cure.

[Applause.]

Ms. SHRIVER. I retired my purple dress. I am going to go get a new one to come back here.

Senator FISCHER. Hopefully you will not need to.

Ms. SHRIVER. Okay. Thank you.

Senator TILLIS. I was about to say, well, I hope to never see you again.

Ms. SHRIVER. Oh, okay.

[Laughter.]

Senator TILLIS. In a good way.

Ms. SHRIVER. We just met.

Senator TILLIS. Thank you so much for coming. And do we have any of the North Carolina group in the crowd here that I met with earlier? Thank you all for coming back. This is the third year that they have been back, and this is something that I was interested in when I was Speaker of the House. We worked on the things that are within the State purview. A lot of that had to do with caregivers.

Ms. SHRIVER. Right.

Senator TILLIS. That is one thing that I happen to agree with you. The fact that you came here because you think that NIH funding is at risk and that is a real problem, and it is a problem that we need to solve by just simply making this a priority. And I think

that you have a number of people here who are going to work to do that.

You know, it is the head-meets-the-heart policy. When I was Speaker of the House in North Carolina, I said that the policies I like the most were the things that have an enormous impact on an individual and their families and saved a lot of money.

Ms. SHRIVER. Right.

Senator TILLIS. That then freed up resources for so many other things that we need to do. So I think we just need to better educate our members who think that there is not a compelling fiscal reason for doing it. It is not the primary reason. It is a secondary benefit for actually trying to help people who have this horrible disease. So thank you for your advocacy.

But I want to talk about things that we also need to do for the caregivers and things that we need to do to educate people who are—just because of the numbers—going to go through this, and understanding what they need to do to make this horrible journey that a loved one is going to go through manageable.

So what else can we do or what other things should we be looking at as matters of priority. Things that are working in one area that need to be nationalized to better prepare caregivers for the hard task that they have to help their loved ones?

Ms. SHRIVER. Well, I think you are going to hear from some people who are doing that 24/7 in just a few moments, and I think they would be able to better advocate exactly what would help them. Every caregiver that I have met—and I have met thousands and thousands, be they men or women. And I just want to say even though my focus is really on women, I have met extraordinary men—Bob is sitting right here behind me—extraordinary men who make it their priority to care for their loved ones, great stories of love and commitment and sacrifice going on in this country day in and day out.

Most of them say they need a break. They need time, because very often the caregiver gets sicker than the actual person that they are caring for. They need someone to come in and help them, someone they can afford, so that they can have some time to focus on their own mental and physical health. So I think routinely you hear that, making it affordable and that the person that they can actually hire is well trained in what their loved one needs. So we need a caregiving force.

As I said, when I was looking for a caregiver for my father, no one was trained in what it took to deal with someone who has Alzheimer's, so they did not understand how he might be different from somebody else that they were assigned to care for. So I think they would advocate and I think they will tell you we need a trained workforce, and trained in the different forms of dementia and different brain-related challenges, right? They need to be able to afford caregiving so that they might be able to continue to be the provider in their family.

As I mentioned with Pam being diagnosed, she quit her job, and Bob had to quit his job as well. That is not sustainable for families, right? And that is what is happening because it is a 24/7 job.

So I think that being able to afford caregiving, being able to find educated caregivers and a workforce, as I said, that is capable of

handling the tsunami, also to encourage people to go into this line of work—it is a growing line of work—paying them a living wage, an educated workforce, and that is really, I know, what you want to talk about as well today.

Senator TILLIS. Well, Madam Chair, I have got another committee that I hope to get back to and ask questions of the panel. Otherwise, I will submit questions for the record. But, again, I think that we need to continue to fight for—I supported the funding, the increased funding for Alzheimer's.

Ms. SHRIVER. Thank you.

Senator TILLIS. I will continue to support it. We need to—also, you made a point in your statement that I think is very important, and it has to do with bipartisanship.

Ms. SHRIVER. Yes.

Senator TILLIS. I am sort of kind of a consulting nerd here, and we have got to think about other ways—as we look for funding, we also need to look for ways to be more productive with the funding that we are producing. And I think this represents an opportunity for Republicans and Democrats to come together and look at some of the hurdles, whether it is research, regulatory environment, authorization for new therapies, those sorts of things that we can look at and find ways to remove barriers to get more productivity and a faster path to treatments and a cure. And it is something that we need to focus on, not just talk about it, because we talk about it a lot, but focus on it because I think there are billions of potential dollars out there beyond what we are putting in NIH that we can unleash and accelerate that time to a cure.

Ms. SHRIVER. I think absolutely, and accelerating certain drugs, that is another thing, obviously, that a lot of researchers who have said it just takes forever to get anything through the pipeline. So I think, Senator, you bring up a really good point to look broadly at the research, at the FDA approval process. How do we get certain drugs that might be promising into the pipeline quicker?

So I think that is exciting to me that you are willing to look at that, because as I said, in the long term this is something that will save our country billions and billions of dollars. So this is an example for the country where Democrats and Republicans can work together. This is a perfect example of an issue where head and heart can work together, and where it does not make economic sense not to work together. Whether you even look at it in terms of humanity, whether you look at it in terms of fiscal responsibility, it all lines up. That is why it is so incredulous that we would even think about cutting it instead of expanding it, because it is impacting so many families of both political parties, Independents, Greens, you name it. It is an equal opportunity offender.

So I think we can put our brains together and say this works on every level. Let us increase the funding. Let us look at the pipeline for drugs. Let us look, as you said, at all different hurdles that might be impacting research, and look at it holistically just as I have been talking about, trying to look at the brain and the body holistically, trying to look at the issue holistically. Alzheimer's is one form of dementia, right? And there are many forms of dementia. But it is leveling our families all across this country. So I wel-

come the fact that you are willing to look at all different aspects of it.

Senator TILLIS. Thank you.

Ms. SHRIVER. Thank you.

Senator TILLIS. Thank you, Madam Chair.

The CHAIRMAN. Thank you very much, Senator.

Senator Blumenthal?

Senator BLUMENTHAL. Thank you, Madam Chair. And thank you for being here today. Thank you to you and your family for taking on so many powerfully important causes, and I am not going to embarrass you and them by going through the list. But you have been such a great champion of this cause, and I think the turnout that we see today shows the growing American awareness and support for it. And all the more incomprehensible the budget cuts that have been proposed by the President, 18 percent in HHS, including \$5.8 billion in cuts to the NIH research budget. We should make no mistake that the axe will fall on the type of research that is so critically necessary, irrefutably and indisputably important.

I am very focused on the aspect of this issue that you raise not only from the point of view of individuals, civilians, but also veterans.

Ms. SHRIVER. Right.

Senator BLUMENTHAL. And I have helped lead the efforts on the Veterans' Affairs Committee and in the Senate to try to deal with the invisible wounds of war, which we know afflict 30 to 50 percent of everybody coming out of combat, the impacts on the brain, post-traumatic stress disorder, not even diagnosed until the 1980s, but leading to dementia and Alzheimer's for reasons that we still are exploring through research.

In that sense, you know, I was struck by what you said about the caregivers, where the VA and the Federal Government have only begun recently trying to help people who deal with folks who are afflicted with this disease. They need a break. They need support in insurance and counseling, in financial wherewithal, and in basic understanding and support, because all too often we think of the hero as being the wounded warrior, which he or she is, but the unsung heroes are also the caregivers.

Ms. SHRIVER. Right.

Senator BLUMENTHAL. So I have been very glad and grateful that Senators Collins and Baldwin have supported legislation, S. 1719, the RAISE Family Caregivers Act, which begins to work in this direction. I would be very interested in more specific recommendations that you have for what we can do to help the caregivers.

Ms. SHRIVER. Well, as I said, you know, I think individuals who are dealing with this 24/7 would best be able to describe what they feel like they need. I am aware of your extraordinary work, and this is an area where so many veterans have come up to me actually looking at different forms of post-traumatic stress, looking at different kind of innovative things they think are working on the brain—magnetic treatments on the brain that at not FDA approved that seem to be helping. But once again, when we talk about Democrats and Republicans working together, the brain, working on finding therapies, working on finding—making the FDA approval process speedier for things that work on the brain is a huge

open space that, once again, veterans can work alongside caregivers.

I think oftentimes when we talk about caregivers, people think of it as a soft issue. You know, a long time ago, when I was getting into journalism, people used to say, "Go do women's issues." And I am, like, "What are women's issues?" They are, like, you know, "Caregiving, women stuff." And I am, like, "That is hard stuff," right? You know, caregiving, there is not anything more muscular—

Senator BLUMENTHAL. Harder than what we do.

Ms. SHRIVER. Yes, but caregiving, as I have written numerous times, that is muscular, that is tough. You have got to be unbelievably strong to do what the men and women in this room are doing 24/7. And as late stage happens, you have to be physically, mentally, emotionally, and spiritually, like, you know, unbelievably strong.

So I think that these families need support, obviously, as I have said before, financial support, emotional support, time. They need to know that they can continue to care for their family and their loved one, and so they need support with that, whether it is through Medicaid, Medicare, you know, they need that. And they need hope. I think hope helps us all, right? Hope that the Government is funding therapies and research and supporting caregivers at a level that we are not seeing today. I think when people have hope, they can get through all kinds of hoops in their daily life. When there is no hope, when they hear that funding is decreased, when they think there is no hope to get a trained workforce out there, it is hard to keep going, right? It is hard.

But I think, you know, there are people in this room who can better describe what they are up against 24/7 than I probably can.

Senator BLUMENTHAL. Well, if it gives them any hope, I hope you will give everyone you are in contact with the message that on this Committee and I think in the Senate there is a lot of support for what you are doing and that we will fight these cuts that are proposed.

Ms. SHRIVER. Thank you.

Senator BLUMENTHAL. That we will work—

[Applause.]

Senator BLUMENTHAL. That we will work for this cause, and if there is one truth about American democracy that has been reaffirmed for me in recent weeks, it is that people can make a difference.

Ms. SHRIVER. Amen.

[Applause.]

Senator BLUMENTHAL. That every individual can make a difference.

Ms. SHRIVER. And, you know, as Senator Collins knows, I have been at this for 14 years, and every time I thought, "Okay, maybe now. Maybe now." But I have never been more hopeful than I am today because I think people are engaged—when you talk about our democracy, people are engaged. They are savvy about their voices and their votes. They know a lot more about the process, I think, in the last year than perhaps ever before. People are engaged in our civics. They understand what an Executive order is and

is not. They are aware of what NIH funding is and what the implications of cutting it are, which is why you see so many people here. And they are not going to take it. They are not going to step back. They are calling their Senators and Congressmen.

[Applause.]

Ms. SHRIVER. And I think that is exciting. I think it is exciting, but it also ought to put everybody on Capitol Hill on alert, because people get it now. They get the power of their voice, and they get the power of being here, and they are not going to take these cuts.

Senator BLUMENTHAL. Well, thank you very much for your eloquence and your advocacy.

Ms. SHRIVER. Thank you.

Senator BLUMENTHAL. And for helping to enliven and educate the American public.

Ms. SHRIVER. Thank you.

Senator BLUMENTHAL. And I would just leave you with this quote, and I am way over time, so I apologize. Margaret Mead said—

Ms. SHRIVER. Yes. I will say it with you.

Senator BLUMENTHAL. [continuing]. “Never doubt”——

Ms. SHRIVER. “Never doubt that a small group of people can change the world.”

Senator BLUMENTHAL. [continuing]. “a small group of intelligent and committed people can change the world.”

Ms. SHRIVER. “In fact”——

Senator BLUMENTHAL. “It is the only thing”——

The CHAIRMAN. “. . . that has ever has.”

Senator BLUMENTHAL. [continuing]. “that ever has.”

Ms. SHRIVER. Amen.

[Applause.]

The CHAIRMAN. Senator Donnelly.

Ms. SHRIVER. I have that above my computer.

Senator DONNELLY. Thank you, Madam Chair. Thank you so much, Ms. Shriver.

I just want to say as an aside that my home town is South Bend, Indiana, and your family brought the Special Olympics there many years ago.

Ms. SHRIVER. Yes.

Senator DONNELLY. And it was one of the most extraordinary times not only in my life but in our town’s life. And we are still grateful to this day for all that you did to bring the Special Olympics there and for all the special moments and special athletes who were there to celebrate. We really enjoyed it.

Ms. SHRIVER. Thank you. I remember being there myself and my mother saying, “You should go confess to Father Hesburgh.”

[Laughter.]

Senator DONNELLY. Well, we were all in line for that, I assure you.

One of the things I wanted to ask you was, how much hope does it give you when you look at where the research is now compared to where it was just like 2 or 3 or 4 or 5 years ago? It is moving pretty fast, isn’t it?

Ms. SHRIVER. It is moving pretty——

Senator DONNELLY. But not fast enough.

Ms. SHRIVER. But not fast enough.

Senator DONNELLY. Right.

Ms. SHRIVER. I would be lying to you if I said to you, "Oh, I am really excited." But I actually am really hopeful. As I said, I have been at this for 14 years, and when I first started, people did not even utter the word. It was always said in a whisper. People had no understanding of Alzheimer's. They did not really face it person to person. Now I do not go 15 minutes on the street or anywhere else without somebody coming up to me talking about how they have been impacted. I meet young people going into neuroscience because their grandmother or their grandfather got an Alzheimer's diagnosis. I meet men and women who are engaged in, you know, advocacy and finding cures or going into daycare or going into the health care business because they have come face to face with this. And I meet a lot of really, you know, young entrepreneurs who are developing apps, trying to deal with caregiving demand, who are trying to find the science, who think maybe they can do something that the Government cannot do. So there is a lot of energy around this from the business world, from young people, from advocates.

But do I think there is a cure around the corner? I do think there is a cure—and I said this last night—in some dish somewhere waiting to be funded, waiting to come over the final line. I have to be that hopeful; otherwise, I would not be here, and I would not be this optimistic.

So do I know where it is? No. But do I think it is within our grasp? Yes.

Senator DONNELLY. I have always thought that is one of the magic parts of the NIH, is that when you said it is in some dish somewhere, that when you go talk to them and you go, "Well, which one is it?" and they go, "Well, we do not know, and that is why we have so many places that we are working with."

And so I have always thought, and as you just commented, that one of the great things they do is we are not chasing this with one line. We have got 30, 40, 50 fishing lines out there to try and catch this cure at some point.

Ms. SHRIVER. I think we probably need 100 fishing lines out there. And I would advocate that we need more fishing lines out there in a broader sense, because I think we have been having some fishing lines in some main areas, and I think we need to broaden that. That is why I am trying to raise money for women-based research, and I am saying, like, "Okay, that did not work, that did not work. Let us look here. Let us look at places that we have not looked. Let us try to move it along quicker, and let us look at what we have not looked at as opposed to continuing to look at what we have looked at that has come up empty."

Senator DONNELLY. You mentioned that two-thirds of folks who have been afflicted with Alzheimer's are women. Have you seen any research that gives you an idea why?

Ms. SHRIVER. No, and that is why I am kind of doing this 24/7, because "I do not know" is unacceptable. And I go around to different labs, and I say, "Well, have you studied women?" And they are, like, "Well, no, but we will now." And so I think it is just—you have to also remember, I think, this is quite new in a way. It has not been around in the consciousness or in the awareness as

long as cancer. And it does not seem to have had the same urgency as AIDS, for example.

But I think we are now at a place where it does. Advocates have become much more forceful. We are marketing it actually in a different way. I think encouraging researchers to look at women in ways that they had not looked at before is exciting to them. Women do have different chromosomes, inflammation. They do process it differently. Having people look at it as maybe perhaps Type 3 diabetes, to look at maybe 20, 30 different ways of looking at it is an exciting space that did not exist before.

Senator DONNELLY. Well, I am just about out of time, but I will make you one promise, and this is to everybody here, and I know the panel feels the same way. I promise you those NIH cuts, they will never happen. So you do not have to worry about it.

Ms. SHRIVER. Amen.

[Applause.]

Ms. SHRIVER. Thank you.

Senator DONNELLY. Thank you.

The CHAIRMAN. Thank you, Senator. I agree.

Senator DONNELLY. And she is more powerful than me.

[Laughter.]

The CHAIRMAN. I am delighted to call upon another new member of our Committee whose birthday happens to be today, Senator Cortez Masto.

Senator CORTEZ MASTO. Thank you.

The CHAIRMAN. Happy birthday.

Senator CORTEZ MASTO. Thank you so much, Madam Chair, Ranking Member. Thank you for having this discussion. And, Ms. Shriver, thank you so much for what you do and being a voice. I always feel that education is that first step in prevention in any manner, and we do not do enough of it at times.

And to everyone who is in the room today, being a voice on Capitol Hill for addressing the importance of brain health and Alzheimer's, thank you for being here.

I really just have a comment. In 1990, my grandmother, whom I am named after, had Alzheimer's, and that was at a time when we really did not understand it. We did not have enough health care programs for it. She, unfortunately—she was one of the smartest women I ever met, and tough and active in her community, and she came down with this horrific thing in Nevada. And my grandfather was her caregiver, and my mother was her caregiver, and my aunt was her caregiver, and my cousins and I and my sister, we were all caregivers. And I remember thinking—she eventually passed away in a nursing home, and I remember thinking, walking in the nursing home, thank goodness at least she had family around here, because there were people there that did not. And to me, that is part of the tragedy of this horrific disease, that I feel that we need to be spending the money for the research for the cure.

I do not know about how you feel, but we are in a state in history right now where baby boomers are aging out, that health care is going to be—the costs of health care are going to be an issue. And when it comes to brain health, that is one of the most important areas that we should be focused on, doing the research, looking for

cures, looking for therapies, and then providing support for caregivers when they have a loved one who is dealing with this issue.

And I have to put a plug in for the Lou Ruvo Center for Brain Health that is in Las Vegas.

Ms. SHRIVER. The Women's Alzheimer's Movement funds researchers at the Lou Ruvo Center and the Cleveland Clinic.

Senator CORTEZ MASTO. Thank you. And for that reason—and I have had the opportunity to sit down with them, and we do not have a cure yet, but with the research, we can at some point in time. You are right. It is there. It is waiting to be discovered. There are doctors there, there are people there that are focused on it. So I can promise you this—and I spoke to the group that was in my office earlier. This is my commitment: to continue to fight for the funding. I do not have to tell you, we all agree. We are going to stop and fight against any cuts to NIH. But we should be looking for additional funding that supports the research and the therapy and the support for the caregivers.

This is such an important issue for all of us but, more importantly, for our futures, and I cannot—I do not think that the money is wasted. This is an area where we should be taking our taxpayer dollars and investing in the future of brain health in this country. And so I appreciate you all being here, and I just had—

[Applause.]

Senator CORTEZ MASTO. I just wanted to make that comment and make you aware you have got a partner already in me, and I will always be there and supporting.

Ms. SHRIVER. Thank you, Senator. I think one of the things you said about education, I think that is a huge aspect of this, is educating people about the power that exists in them to control their health. I think this is a big thing that doctors and researchers are talking about precision, personalized medicine, trying to understand what works for your body, what works for your brain. That is where the future of health care is going, right? So that there is no one—as one doctor said to me, when my father was diagnosed, “Once you have seen one case of Alzheimer's, you have seen one case of Alzheimer's.” It is a complex disease. But we need to encourage people starting in their 20s and 30s to take control of their health, to be educated about the pros and cons of different treatments, to be involved in their own physical, mental, emotional, and spiritual health.

Senator CORTEZ MASTO. I agree. Thank you. Thank you for being here.

Ms. SHRIVER. Thank you.

The CHAIRMAN. Thank you very much, Senator.

Ms. Shriver, on behalf of the entire Committee and everyone in this room and all throughout America and, indeed, the world who have benefited so much from your advocacy, thank you so much for being here today.

Ms. SHRIVER. Thank you, Senator.

The CHAIRMAN. You are a powerful voice. Thank you.

Ms. SHRIVER. Thank you. Thank you, Senator.

[Applause.]

Ms. SHRIVER. Thank you so much for having me. It has been an honor, and I just want you to know how moving it is for me to be

here amongst all of these incredibly brave and inspirational men and women who are taking their own personal time to be here to speak to all of you, to visit you in the offices. It is one of the most humbling experiences of my life, and I have had a lot of different experiences. But to be amongst these people who are fighting for their loved ones and are fighting for their own health is really an honor and a privilege. And I hope that you fund this disease, and I hope that Pam Montana and others like her who stand behind her become the survivors of this disease.

So thank you very much for having me.

The CHAIRMAN. Thank you.

[Applause.]

The CHAIRMAN. We are now going to move to our second panel of witnesses, and we thank you again so much for appearing today.

[Applause.]

The CHAIRMAN. Our first witness on the second panel is Dr. Kristine Yaffe. Dr. Yaffe is vice chair of research in psychiatry at the University of California, San Francisco, School of Medicine. She serves as a professor of psychiatry, neurology, epidemiology, and biostatistics. In other words, she knows everything.

[Laughter.]

The CHAIRMAN. She is also chief of neuropsychiatry at the San Francisco VA Medical Center. In 2014, she was recognized as one of Thomson Reuters World's Most Influential Scientific Minds.

Next I am going to turn to my colleague Senator Donnelly to introduce Dr. Christopher Callahan.

Senator DONNELLY. Thank you, Chairwoman Collins.

It is my pleasure to introduce a fellow Hoosier, Dr. Chris Callahan, from Indiana University. Dr. Callahan is the founding director of the IU Center for Aging Research and has over 25 years of experience studying new models of care for older adults. He is also a professor at the IU School of Medicine, a research scientist in the Regenstrief Institute, and director of the Eskenazi Office of Applied Research. His work focuses on improving the ways that we care for people living with dementia, depression, and other similar conditions.

Dr. Callahan was part of the team that conducted the first randomized controlled trial of collaborative care for patients living with Alzheimer's. He has since led several other clinical trials designed to improve care for older adults with Alzheimer's, and he continuously seeks to develop models of care that integrate family, community, and medical professionals.

Despite improvements in recent years, many challenges still remain to providing quality care to all people with Alzheimer's. Medical workforce shortages impact access to care, new and innovative models can be expensive to implement, and rural Americans can find themselves far from the resources they need. Dr. Callahan has been acutely aware of these challenges, and his research is helping improve the way we care for people with Alzheimer's and ensure that quality treatment becomes widely available.

Dr. Callahan, I want to thank you for your important work. We are so proud of you and everything you are doing, and we are very, very glad to have you here today. Thank you for being here, sir.

Dr. CALLAHAN. Thank you very much.

The CHAIRMAN. Thank you.

And now I would like to turn to our Ranking Member, Senator Casey, to introduce our witness from Pennsylvania.

Senator CASEY. Thank you, Madam Chair.

It gives me great pleasure to introduce a fellow Pennsylvanian. I made reference to Phyllis Gallagher in my opening statement today. Phyllis is a caregiver. She lives today in Frackville. Schuylkill County, correct? Phyllis, I was late for the hearing, and I did not have a chance to say hello to you personally, but we are really grateful you are here.

Phyllis, like so many in the audience, cares for her loved one, in this case her husband, John. John is a former Pennsylvania State employee. So am I. And we are grateful that Phyllis is here to talk about the challenges she and her family have faced.

John began showing symptoms of early-onset dementia when he was just 49 years old. That was 9 years ago. Phyllis cared for John at home for as long as she could, and John had to transition to a residential facility. In addition to caring for John, Phyllis is an advocate for individuals living with Alzheimer's and their caregivers. I am very grateful she is able to be with us today to share her family's story.

Phyllis, thank you.

The CHAIRMAN. Thank you very much, and we will start with Dr. Yaffe.

STATEMENT OF KRISTINE YAFFE, M.D., SCOLA ENDOWED CHAIR AND VICE CHAIR; PROFESSOR, DEPARTMENT OF PSYCHIATRY, NEUROLOGY, AND EPIDEMIOLOGY AND BIOSTATISTICS, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO; AND CHIEF, NEUROPSYCHIATRY, SAN FRANCISCO VA MEDICAL CENTER, SAN FRANCISCO, CALIFORNIA

Dr. YAFFE. Thank you, Chairman Collins, Ranking Member Casey, and members of the Committee, for the opportunity to testify today about one of the most important issues of our time: Alzheimer's disease. This has really been a remarkable afternoon so far.

Alzheimer's disease is a brain disease and the most common cause of dementia, a syndrome of cognitive changes usually associated with aging. Alzheimer's results in memory and other cognitive symptoms from a complex accumulation of proteins, including beta-amyloid and tau, that leads to the death of nerve cells. Despite tremendous advances in brain science over the past few decades, there is still so much to learn. It is unclear why some people get the disease and others, who have may have evidence of the proteins, do not get the disease. Furthermore, despite great effort, we still do not have good treatments.

What we do know for sure is that Alzheimer's disease is devastating. As you heard from others, it carries a tremendous toll on the patient, the caregiver, our health care system, and society. We need to change this trajectory through the development of effective treatments and, ideally, prevention.

One of the most conceptual and interesting changes in the field over the last few years is we now know it takes decades for the abnormal proteins to develop. Therefore, we have the opportunity to

prevent, even before symptoms—to delay or even prevent Alzheimer’s. We are finally in a position to study this, and this has evolved into two very important strategies: one, studies of risk factors that might be modifiable; and, two, studies of new drugs for people at risk.

There is emerging evidence that several factors may increase the likelihood of developing Alzheimer’s in addition to genetics. Many of these risk factors are modifiable and good targets for both individual and public health strategies.

One of the things we have learned—and Senator Casey referred to—is that what is good for the heart is good for the brain. Why is that? That is because some of the same issues, like hypertension, diabetes, high cholesterol, also affect the risk of Alzheimer’s. We think there is about a 50-percent increased risk of developing Alzheimer’s with these factors. The exact mechanism is still to be worked out, but most likely it is an effect on the blood vessels and also increasing the protein amyloid.

Several trials are underway to see if diabetes, cholesterol, and blood pressure medications may actually protect against developing cognitive impairment, but we need more research to understand how and when these heart health factors may impact brain health. We heard from Ms. Shriver that it may actually be important to intervene earlier in life, in the 20s and 30s, not waiting until somebody is 70s and 80s, a very important issue.

The concept of cognitive reserve has also been proposed as an explanation for why some people are able to tolerate the brain changes with Alzheimer’s and yet others cannot. This is this idea that maybe even with the brain changes you can tolerate and do not have symptoms, and it is exciting because now we have some opportunities to maybe promote resistance to Alzheimer’s. Factors that contribute to cognitive reserve include physical activity, education, and cognitive stimulation. Studies support this idea that being more active, both in body and in mind, may prevent Alzheimer’s. But more work is needed before making definitive conclusions.

Traumatic brain injury, TBI, is a common condition that peaks in early adulthood and actually has a second peak later in life. Many studies have reported that moderate and severe brain injury increases the risk of dementia, but there is much less known about more mild TBI, otherwise called “concussion,” and whether this also increases risk of dementia. The studies are much more controversial. So, clearly, we need more research in this area as well.

An area of recent discovery has been the connection between sleep and Alzheimer’s. This is a fascinating area of investigation. It suggests that during sleep, proteins are cleared out from the brain. We do not really know what sleep is doing, but maybe it clears out the proteins. Therefore, if sleep is disrupted due to sleep apnea or insomnia, the proteins might accumulate and lead to greater chance of Alzheimer’s. We do not know if treatment of sleep disorders might improve Alzheimer’s or delay it, but many are interested in exploring this.

Some argue that these modifiable risk factors will never cure Alzheimer’s. For this, it is clear that we do need better drugs. However, because these lifestyle factors are so common and can be

changed—and without side effects—we could have a big effect on both the individual and society. Studies suggest that if people could reduce these risk factors by a modest amount—say 10 to 25 percent more physical activity, or 10 to 25 percent better hypertension control—we could see a big effect on the downstream effect of the number that develop Alzheimer's. Many countries have conducted trials in which these factors are addressed in combination, and preliminary results look quite good. We need to have such trials in the U.S.

There has also been tremendous interest in developing more effective drugs for Alzheimer's to see if these may prevent the disease. In the U.S., there are four ongoing pharmacological trials testing possible prevention of Alzheimer's for people at risk for the disease, either because of genetics or evidence of the protein accumulation, but they do not have symptoms. These trials are critical in order to identify better treatments as early in the disease as possible. Most of them target the accumulation of abnormal proteins, and in this way, it may be possible to prevent or delay the disease.

Some experts, including myself, think that someday Alzheimer's will be like chronic heart disease with several available drugs that treat different aspects of the disease. It will not be the devastating diagnosis it is today but something that can be slowed and treated. In addition, these drugs will be combined with lifestyle modifications. Clearly, in order to do this, we need more research. While the field has come a remarkably long way from when, just a few decades ago, people thought dementia was normal aging, we still have a long way to go.

In 2011, the bipartisan National Alzheimer's Project Act that you, Chairman Collins, co-authored became law and provides hope to conquer Alzheimer's. I urge you to support the fiscal year 2018 bypass budget, and I thank you for all your interest and time and all that you do.

The CHAIRMAN. Thank you so much for your very interesting testimony.

Dr. Callahan.

STATEMENT OF CHRISTOPHER M. CALLAHAN, M.D., DIRECTOR, INDIANA UNIVERSITY CENTER FOR AGING RESEARCH, AND INVESTIGATOR, REGENSTRIEF INSTITUTE, INC., INDIANAPOLIS, INDIANA

Dr. CALLAHAN. Good afternoon, Chairman Collins and Ranking Member Casey. I also want to thank Senator Donnelly for that very warm introduction. And thanks for the opportunity to speak with you today.

I am going to talk a little bit about some exciting work on new models of care, but I want to talk first about how care can go really terribly wrong for people with Alzheimer's disease. And I want you to imagine for a moment your elderly widowed mother. Maybe she is 76 years old, and she appears to enjoy wonderful health. But maybe you have noticed some things. Maybe you have noticed an accident in the kitchen or maybe an accident in the car. Maybe you have noticed her repeating herself. But she seems happy, and she maintains a clean home, which you help out with. And so you keep your concerns to yourself.

Then you get a call from the neighbor, and the neighbor says your mom walked into their home last night and was rude and disheveled. And as you investigate further, you find that your mom's finances are in a shambles. Her bank accounts have been drained by a heartless scammer. She has overdue utility bills. You take her to visit with her physician, and he says he saw the signs, but he did not want to break her spirit.

Later that year, she falls and fractures her hip. She seems to be ping-ponging between the hospital and the nursing home. She is on a dizzying array of medications and also bouncing between doctors. And you feel completely alone.

I know stories like this will be played out multiple times this year and in coming years. And while that story is tragic, I am certain that someone behind me can tell a story that is much more tragic.

It does not have to be this way, and that is what I was asked to talk about. To make the journey of Alzheimer's disease less painful, we all have to do better. Good care for failing brains begins with an early and an accurate diagnosis. Many things can look like Alzheimer's disease, and it is easy to dismiss the early signs. But a failing brain is not normal aging. Once a patient receives a diagnosis of dementia, there is a complex road ahead. We have to give the caregiver education and support as well as the care recipient. There is a lot of decisionmaking in front of them. There are treatments to consider and lots of care planning, including financial planning.

People need to know their new vulnerabilities and the services and supports that are available to them. But now there are road maps. Research on models of care that has been funded by the NIH, the VA, AHRQ, the Hartford Foundation, the Center for Medicare and Medicaid Innovation. They show that we can improve care. New models of care integrate the health care system with our community and our social support services.

I am going to give just one example of this research. Scientists at Indiana University tested an approach known as the "Collaborative Care Model" that Senator Donnelly alluded to. That model provided primary care physicians and their patients with enhanced screening and a companion diagnosis program. For patients diagnosed with dementia, the model provided care management through an interdisciplinary team. That team was led by an advanced practice nurse working with the patient's family and integrated with primary care.

Families were referred to the Alzheimer's Association to get the support that is already available there. Both patients and family caregivers in that study had improved symptoms, they were more satisfied with the care, and they were less likely to receive harmful drugs. Similar models have been tested at UCLA and Johns Hopkins among many other places.

In a report published just this month in Health Affairs, using another model, also a nurse-led intervention for persons with dementia in the nursing home, they showed that they could decrease unnecessary hospital use and they could decrease overall Medicare costs.

The sad news is that these models are not reaching the millions of Americans who could benefit. Older adults in rural America are often hundreds of miles away from even basic services. The main problem is an inadequate workforce.

New models of care need to expand the reach of our limited physician workforce. This might include training nurses, social workers, or other professionals to provide these services. However, even that workforce is inadequate, as the Institute of Medicine has documented. Our country needs a very large increase in the number of direct care workers who can provide hands-on care for older adults with Alzheimer's.

I will end by saying, though, if there is one reality that I could best highlight, it would be this: Family caregivers are the hands, the backbone, and the heart of the Nation's workforce for Alzheimer's disease. This will not change over the next 25 years. Family caregivers will sacrifice their sleep, their health, their finances, their careers, and their friends to provide care in the home for as long as possible for their loved one with dementia. They will do it, but they should not have to do it alone. So often, we hear family caregivers say at the end of their draining 10-year journey that they wish they knew then what they know now. The best way to help persons with dementia is to help their family caregivers.

Thank you.

[Applause.]

The CHAIRMAN. Thank you very much for your testimony, Doctor. Mrs. Gallagher.

**STATEMENT OF PHYLLIS GALLAGHER, FAMILY CAREGIVER,
FRACKVILLE, PENNSYLVANIA**

Ms. GALLAGHER. Thank you, Chairman Collins, Ranking Member Casey, and members of the Committee, for the opportunity to testify today on the toll of Alzheimer's and other dementias. As a caregiver for my husband, John, I hope my story will shed some light on the reality of this cruel disease.

My husband, John, and I have been happily married since 1993. John is the nicest, kindest man. We had fun together. Prior to his diagnosis, John was healthy as a horse, 6-foot-2, 260 pounds, and he went to the gym every day. He ate well, though he is a good Irishman and did enjoy a beer here and there. John worked in the Pennsylvania State Capitol in a job he enjoyed. He was very social and was living a full life.

After his father passed away in 2008, I started to notice that John was having a harder time finding his words. As we would later learn, this was the start of our journey with Alzheimer's. And John was only 49 at the time.

We started with our primary care doctor, who thought John might be suffering from a stroke or depression and anxiety following his father's death. When John did not get better, we went back to the primary care doctor 6 months later, which was then followed by a visit to a local neurologist. We had no new answers, and months went by as John continued to struggle with his speech and was showing more erratic behaviors. John was physically healthy. It was his brain that was not.

After months of unanswered questions and new combinations of medications to address the symptoms, John started seeing a psychiatrist. The psychiatrist was the first one to suggest that these symptoms could be memory-related. I tried to get John in to see a specialist at several facilities in Pennsylvania, but each of them had a 6-month wait. The Memory and Alzheimer's Treatment Center at Johns Hopkins had a 3-month wait, so that is where we went. If there were more trained specialists in this field, we might not have had to wait so long or travel so far to see someone.

After our 3-month wait, John and I made the first of what would be many drives from our home in Frackville, Pennsylvania, to Baltimore, Maryland, for John to have a full neurological work up at Johns Hopkins. The team at Hopkins wanted to use a PET scan as part of their diagnostic process, but, unfortunately, it was not covered by our insurance. After a wave of testing, John was officially diagnosed with Alzheimer's disease.

He retired from his job in March of 2012, and we decided to do what we could to help the next person going through this disease. It was extremely important to both of us that we not be complacent. We got involved with our local Alzheimer's Association chapter. We walked together in the Walk to End Alzheimer's. John participated in several research projects at Hopkins and in one of them was finally able to get that PET scan. He also decided that he wanted to donate his brain to research after he dies. As John put it, "They might not be able to help me, but what if my girls get it?"

We also decided to live our lives fully while John still could. We went to Ireland for our big bucket list trip. We went out a lot with friends. We made regular trips to New York to see his oldest daughter. I did anything to make him happy in the course of this, and we had as much fun as we could.

That does not mean we did not face our share of challenges. As time went on, John always needed supervision. If I needed to take a shower, I would have a neighbor come over to watch him. I would do things around the house at night while he was sleeping. And the first time you have to help your spouse in the bathroom is traumatic, and people do not tell you about that.

Because of his age, John was not eligible for many programs available to people with Alzheimer's. Many of these programs are only for people over the age of 60. Or they are aimed at people with physical disabilities. I could get help if he had lost a limb, but I could not because of dementia. If you cannot find someone to help you, you are stuck. I was able to get John into an adult day program two to three afternoons per week. And what a relief that was. I could go grocery shopping or run other errands without worrying about John.

The difficulty in communicating was a surprise. When he could not find his words or had trouble speaking, we had to communicate through what I came to call "Charades of the Gallaghers." We had as much fun as we could in such dire circumstances.

After John's diagnosis, we talked a lot about what he wanted as the disease progressed. We talked about the likelihood of John needing to be in a nursing home one day and planned his funeral. I remortgaged our home, hoping to care for him at home as long

as I could. We renovated our first floor to include a full bath and a laundry room and to make the home handicap-accessible to anticipate his future needs.

Medicaid helps to cover the cost of John's nursing home, but I still pay \$1,850 a month out of pocket. That means that I do not go out unless a friend can pay for me. I work with a limited grocery budget. I participate in activities that do not cost money so that the resources I do have can go to my husband's care.

When someone has Alzheimer's, it is not just the person who gets sick. It is the whole family. The disease takes a toll on a community of people. Without our friends, family, and neighbors, I would not have been able to care for John.

John and I believe that you cannot just sit around go and "boo-hoo." You have to do something. That is why I wanted to be here today and why I participated in the Alzheimer's Association Advocacy Forum for the first time this year.

This week, I joined 1,300 advocates from across the country to make a difference here in Washington. We are here to speak on behalf of the 5.5 million Americans living with Alzheimer's today, to advocate for their care, and to fight for more research funding. Alzheimer's is a fatal disease with no means to prevent, cure, or even slow its progression. Investing in research is the only way to change that.

Alzheimer's research is currently funded at \$991 million annually, but the scientists at the National Institutes of Health say they need more to make progress toward ending this disease. Researchers at the NIH asked for an additional \$414 million for fiscal year 2018. As a caregiver and advocate, I am respectfully asking Congress to fulfill that request.

Today John is 58 and in the end stages of Alzheimer's. This disease has ravaged our family, but that does not mean we have to give up hope. Something positive has to come out of this. It is inspiring to be here on Capitol Hill for the first time with so many others like me, and we all are counting on you to take action so we can, once and for all, end Alzheimer's.

[Applause.]

The CHAIRMAN. Thank you.

[Applause continues.]

The CHAIRMAN. Mrs. Gallagher, you are getting a standing ovation. Thank you so much for that heart-wrenching yet inspiring testimony and for sharing your personal story with us.

Ms. GALLAGHER. Thank you.

The CHAIRMAN. Dr. Yaffe, you talked about the potentially major impact that lifestyle changes could have on the incidence of Alzheimer's disease. Why would exercise and diet have an impact on the accumulation of beta-amyloid plaque or tau in the brain? What is the theory?

Dr. YAFFE. I will try and be succinct. It is a great question. Some of these lifestyle factors most likely work by decreasing the amount of amyloid production. A good example might be with sleep, for example, where we know there is this complex interaction between sleep and actually the amyloid accumulating. Other factors probably act in a more indirect way by enhancing reserves, so making

the brain more resilient to the fact that there might be amyloid already there.

We think with physical activity it is probably a multi-pronged effect. There have been beautiful studies showing that the hippocampus actually increases with physical activity, and the hippocampus is the part of the brain most relevant for learning and memory. So there is something going on when people actually exercise. We think it is probably new neurons, new connections.

So it is a fascinating, fascinating area of explanation. We do not have all the answers, but there is a lot of really interesting clues. And so it sounds like, oh, just do a good diet or do this or do that. But most of the things that I chose to discuss are the things that I think have the best evidence and actually have a lot of biology explaining why they may work.

The CHAIRMAN. Is there evidence that a Mediterranean diet also may have an impact?

Dr. YAFFE. Yes, so I did not discuss diet as much because I had a limited amount of time. I would say that the area of diet is a very interesting one, a lot of interest in it, but not as much work that we know so far. So the idea that single nutrients, say vitamins or omega-3, those have been studied and have not worked out so well. The field is now shifting towards more of a pattern of diet, as you allude to, a Mediterranean diet, a healthy diet, where it is not just one nutrient but the whole shebang. And that is looking much more promising, but, again, we still need more work to know, I think, definitively.

The CHAIRMAN. There have also been clinical trials with drugs that have been able to clear some of the plaque tangles from the brain, and yet it appears that it did not restore cognitive function. Do you have a theory about why that is the case?

Dr. YAFFE. You know, that is not exactly my expertise, but I know somewhat about it.

The CHAIRMAN. You know more than we do.

[Laughter.]

Dr. YAFFE. I have been impressed with your knowledge.

I think there has been a lot of hope that if you can get rid of the amyloid in the brain that is the target of many of these drugs, that might then improve cognitive function and delay/prevent Alzheimer's.

It looks very promising, but we are not there yet. So some of the trials have either had to stop because of side effects or they did not work as well as they did in the animal models, again, showing us that the brain, I think, is much more complex than we thought and that this is just going to take more work. But I think we are on the right track.

The CHAIRMAN. Thank you.

Dr. Callahan, so many older individuals rely on their doctors as a trusted source of information and counsel, and you have underscored the critical role that primary care physicians can play. Yet you have also suggested in your testimony that the overwhelming majority of primary care doctors and other allied health professionals have completed little or no formal training in providing care for people with dementia and advising their caregivers as well.

With that in mind, I am concerned by the President's proposed budget cut to the Geriatrics Workforce Enhancement Program because we know, as you illustrated, that there is a real shortage of trained individuals who can help caregivers or even act as caregivers. This is the only Federal program that supports the education of doctors, nurses, physician's assistants, pharmacists, social workers, and many other health professionals who choose to serve our Nation's seniors.

How might these cuts affect the supply of health care professionals who complete training in geriatrics?

Dr. CALLAHAN. Well, one of the sad parts about this, as you mentioned, is that this is one of the few programs left in order to help support the training, and what people may not know is the Geriatric Workforce Enhancement Program is not just focused on physicians. It is focused on nurses and social workers and other care providers as well.

We are lucky at Indiana University in the State of Indiana that we have a Geriatric Workforce Enhancement Program, and it is the singular place also where we can teach doctors how to work in a team. People do not necessarily know how to work in a team. They were not necessarily trained to work on these interdisciplinary teams. They do not know that there is a lot that the nurse working alongside of them could do or the social worker working alongside of them could do.

So the Geriatric Workforce Enhancement Program is almost like, well, this is one of the few things left. Why would you want to get rid of it? So it is very important, and it is exactly the kind of program that we are talking about also that can reach providers who have already left their formal education, because we can go out into their offices and in the places where they practice and show them how to redesign their practices.

The CHAIRMAN. Thank you.

Mrs. Gallagher, I am not asking you questions because I know my colleague Senator Casey is going to ask you a lot of questions, but, again, I want to tell you how moved I was by your testimony.

Ms. GALLAGHER. Thank you. Thank you for having me.

Senator CASEY. Madam Chair, thank you very much.

And, Phyllis, thank you, and I reiterate those expressions of gratitude. I cannot even imagine what you have been through, like so many members of this wider family in the audience.

I guess one question I had was you mentioned that there were times when you were not, you did not think you were prepared for what was happening or you had to provide a kind of care that you may not have had much training in or warning about. Anything in particular you would hope that we would be able to tell people as they are embarking on a caregiving mission, what you did not hear that you would hope that others would?

Ms. GALLAGHER. Well, my mother had Alzheimer's at 80, and with John having it at 50, I did not even realize that could have happened, so I think educating the public in general. I am technically an artist, so believe me, being a caregiver was not exactly in my field. But as a wife, that is what you do. So I did anything I had to. But it would have been easier even to just find help. I called the Agency on Aging in the county and was told, "He is

under 60. We cannot help you at all," and that was that. I was, like, "Okay, well, now what do I do?"

So then, thankfully, there was the Alzheimer's Association, and they helped. Their 24-hour hotline got called frequently at 2:00 a.m. by me. Also, there are various support groups online, which I found very, very helpful to just talk to others in my position, because throughout, especially when some of the support groups are international, so there is always someone awake that you can talk to. So it did not matter what time of day, and hopefully within the group someone had a somewhat similar experience.

But even my experience between my mother and my husband was very different. So, you know, each case is different.

Senator CASEY. And I do not want to bring you back to times that have been particularly difficult, but it is helpful for us to be able to hear direct testimony about what you have had to live through. What is the most difficult part, just in terms of the—in addition to the obvious difficulty of accepting a terrible diagnosis?

Ms. GALLAGHER. The acceptance, the friends and family, because you have some people who go away. You know, it is not contagious, but sometimes you feel like, "Are we contagious?" You know? And you learn who your friends are, and that was one thing.

You are so alone is the other. You are very, very much alone. And then you are so busy taking care of them that, you know, your day—and you have got to feed them, and sometimes it would take from 7 o'clock in the morning until noon just to have him bathed and dressed. And then it is noon, and now it is time to feed him again. So you do not get that time. And to get a break is very difficult, to find someone, especially at our age, because we do not have that many peers who were retired, to, say, "Hey, if you have nothing to do, come on over and sit with him?" So that was hard. I was lucky I had very good friends, and I had a wonderful neighbor across the street who helped me a lot, especially in a pinch. She was a stay-at-home mom. So I was thankful that she was there a lot to help me. And my husband's best friend helped us. Every Monday he sat with my husband so I could go to therapy, and therapy is a godsend for me. My husband also went to therapy when he was first diagnosed as long as he could still communicate. He went also to deal with the issues that we both had, you know, stress-wise, mental health-wise. And I found that to probably be the most important thing in my life, was the help I got from the therapist.

Senator CASEY. I appreciate you sharing that testimony because it is helpful for us.

The last question I have is simple, just your health care coverage. Did you have the benefit of the State Employees?

Ms. GALLAGHER. You bet. Thankfully, because that covered therapy, covered everything but the PET scan. I was going to get a loan for the PET scan because that was \$16,000, and John said, "Why?" So then the doctors at Hopkins thankfully had a research project that involved PET scans, and that is how John got his PET scan.

Senator CASEY. Thank you. I am out of time, but thank you very much.

The CHAIRMAN. Thank you, Senator Casey.
Senator Warren?

Senator WARREN. Thank you, Madam Chair, and thank you all for being here. And thank you, Madam Chair, for the work you have done to draw attention to this crisis in America.

This disease is tremendously painful for families who live through the horrible experience of losing a loved one through it. This disease is also wildly expensive. I know that the Chair talked about this. The United States spends \$259 billion a year on health care related to Alzheimer's disease, including \$175 billion for Medicare and Medicaid. And yet NIH spends less than 1 percent of that amount on Alzheimer's research every year.

[Applause.]

Senator WARREN. Breakthroughs will not happen if we are not funding our scientists and keeping in the fight as they push every day to make progress. So let me see if I can just ask a couple of questions around this.

Dr. Yaffe, you started your work on cognitive decline more than two decades ago. Do we know more about dementia in older adults today than we knew when you first started 20 years ago?

Dr. YAFFE. No question, yes.

Senator WARREN. All right.

Dr. YAFFE. Absolutely.

Senator WARREN. And what role have NIH grants played in your ability to stay in this fight? How many have you received over your career?

Dr. YAFFE. Gosh, I have probably gotten about 15 that I was the lead for and then maybe another, you know, 15 or 20 where I was a co-lead. Obviously, it has been instrumental for me. I could not be doing what I am doing without NIH funding. It is by far the most important funder for research, medical research, you know, by far.

I want to say it is particularly important for young people. We are talking about the importance of the geriatric workforce, but we also need to talk about the importance of the physician scientists and scientists in general who, once they finish their training, they are expected to then get a grant, often a career development award, so that they can get from their training stage to their independent stage. This is critical, and it is critical that the NIH fund this because, otherwise, people are not going to go into science.

Senator WARREN. We will lose our researchers if we do not fund them.

Dr. YAFFE. And, in particular, it is the physician, the clinician scientists who have one hand in with patient care and understand the clinical issues, and then the other trying to solve this problem. I cannot tell you, having served on the review committee for this at the NIA, one of the committees, you saw wonderful people who just did not quite get a good enough score, and you had a feeling they were not going to be able to stay in science. So I cannot emphasize enough the importance particularly for that transition period.

Senator WARREN. That is very important. And if I can ask you, Dr. Callahan, you work in a very different type of research than Dr. Yaffe. Your research examines how to improve the care that older adults with dementia and depression receive from their pri-

mary care physician. Dr. Callahan, has support from NIH also made a difference in your work?

Dr. CALLAHAN. Well, much like Dr. Yaffe said, I would not be here without NIH funding. I think one of the things that we sort of watch as we are marching along is originally the NIH is funding you as an untested junior scientist with career development awards and with an opportunity to go in a very different direction. So they are investing in you, but they are holding you in science through their support. When that is successful, then we move on to independent grant funding. But then the NIH also funds program development at our universities.

So, for example, Indiana University had an Edward Roybal Center, and with the Roybal Center then, again, we splinter off, we are able to attract even more young people from a wider discipline. So at each stage in a person's career, you need the NIH to consistently be there.

Senator WARREN. And I am about to run out of time, but with the Chair's indulgence, I just want to ask you, Ms. Gallagher, I know that caring for your husband was a tremendous responsibility and how painful it must be for you to know that scientists will not be likely to come up with help in time, but that you are still here arguing, advocating on behalf of future Alzheimer's patients and their families and caregivers. Can you just say a word about the importance of research as you see it and funding the NIH?

Ms. GALLAGHER. We need help. We need help, we need a cure. I am worried about my husband's two daughters. The oldest is 32, and I sure would hate to think that she only has 15 good years left. I would hate to think that. She has a 6-month-old and a 3-year-old. So I hope to God that my grandkids and that my kids do not have to worry about this. So there has to be research.

And just to go through, it is a life of almost daily torment of what you have to go through to keep, you know, just everyday life. And it is absolutely necessary. It is just amazing. It needs to be cured, and it needs to be cured, you know, as soon as possible.

[Applause.]

Senator WARREN. Thank you. And I will just be blunt on this. We need more money for NIH, not less.

Ms. GALLAGHER. Yes.

Senator WARREN. We need more money for NIH. Thank you, Madam Chair.

[Applause.]

The CHAIRMAN. Thank you.

Senator Donnelly?

Senator DONNELLY. Thank you, Madam Chair.

To all of you, to Mrs. Gallagher, God bless you in what you are doing. It is God's work in every way, shape, and form. And to Dr. Yaffe, thank you so much for your work. And to Dr. Callahan, we are so proud of you. You are doing such extraordinary things. And as you know, we have a large rural population in our State as well, and you shared that rural Americans often live miles away from necessary services and have difficulty accessing the care they need. Could you elaborate a little bit on the challenges that face rural Americans with Alzheimer's and what we can do to ensure that ev-

everyone with Alzheimer's, rural or not, has access to care and access to help?

Dr. CALLAHAN. Yes, about one out of every five people with Alzheimer's disease is in a rural area, and if you think about how—so all day we have been hearing about how caregivers feel alone and the care recipients feel alone. You cannot really get much more alone than being a caregiver of Alzheimer's disease in a rural area. It is the lack of services. We have heard about today that it is the drive. I mean, it is a lot of work to take a loved one with Alzheimer's disease, you know, put them in a car, drive them 50 miles, and then all of the things that could go wrong in that transportation event.

The other problem that we have is that we have heard about the importance of neighbors and community and church, and sometimes even those are farther away in the smaller communities.

So what people have been trying—Minnesota has been innovative this way and Wisconsin has been innovative this way—is to look at technologies. This has been true for a lot of rural health. Could you use technologies to try to reach people? We heard Mrs. Gallagher say how she was—you know, you can connect on the Internet as long as it is not somebody trying to cheat you or steal from you.

But these services, I think we also have to really reimagine the workforce. Who is it that is in that community already that we could train to help out, even if it is only to come and visit someone for an hour or two? It is a very special challenge.

Senator DONNELLY. It is an incredible burden for that caregiver, isn't it, at the end of the day? Is there almost like a feeling of being overwhelmed at times?

Dr. CALLAHAN. Absolutely, and you hear these terrible stories. There are, you know, stories of a husband who is worried about his wife wandering, and so he ties the two of them together with a string. But what else is he going to do? Because she gets up at night and wanders. Or sad stories where people actually are locking people in because they have run out of options. There is no one to call anymore.

And then, again, in terms of costs, who are you going to call? I mean, when you are finally at wits' end, you end up calling 911. You know, it was not an EMT and a paramedic that you needed. It was, you know, a direct care worker who could help you in the moment and maybe just, you know, to give a bath.

So it is an incredibly lonely experience to be a caregiver in a rural area. And I do not mean to leave the care recipient out. It is hard for them as well.

Senator DONNELLY. Dr. Yaffe, you noted that in many other countries they have conducted multidomain trials to study the impact of several factors together on reducing the risk of Alzheimer's. Is there a reason why these trials have not yet been conducted here in the United States?

Dr. YAFFE. I think there has been a lot more interest in lifestyle and modifiable factors in Europe, in Canada, and Australia, for example. I think the U.S. tends to be a little bit more focused on Pharma and technology, and so I think that is one of the big reasons why.

I think the tide is turning, and, actually, I have put in a grant to hopefully be able to do such a trial in the U.S. And I think there is growing interest, so I am optimistic that we will be part of this research direction as well.

Senator DONNELLY. Well, I want to thank the panel. I want to thank you all for your courage and for your devotion to others in the work you do every day.

Thank you, Madam Chair.

The CHAIRMAN. Thank you very much, Senator.

I want to thank all of our witnesses today for your powerful testimony and for the important work that you do each and every day.

My thanks also to all the advocates who are here, storming Capitol Hill, making the case, arguing for more funding that will lead to effective treatments, a means of prevention, and ultimately a cure.

We are making advances in understanding the arc of Alzheimer's from prevention to cure, and yet that arc is long, and we have a long ways to go.

We know that every 66 seconds someone in our country is diagnosed with Alzheimer's disease, and ending this trend has to be an urgent national priority. We know that we can do better. We can do better in the way that we care for those who are living with Alzheimer's, and we know that we can do better in training our medical personnel, and we know that we can do better in helping our caregivers who put in an endless number of 24/7 days.

And, most of all, we in Congress can do better in funding the vital research that one day will lead to the end of this disease or at least a means of managing it as a chronic disease, as Dr. Yaffe said.

Many of you have traveled long distances to Washington to share your stories and to advance the fight against Alzheimer's. This sea of purple represents hope, and you are making waves. So I ask that you keep at it. You are making a difference.

Our Committee members are also committed to this cause. In fact, I was thinking as I listened to the testimony today that one thing we could do—and I should have talked to you about this in advance—is for us to lead a letter, signed—and we would hope to get the signatures of every member of the Aging Committee—and send a letter to the President in opposition to the cuts to NIH's budget, but also to the Geriatric Workforce Development Fund, which is also important. And I think it would be a really powerful bipartisan step forward if we can get the signatures of every member of this Committee. You are in?

Senator DONNELLY. Madam Chair—

[Applause.]

Senator DONNELLY. I was going to say, Madam Chair, that this Zip code down at this end is also in on that plan as well.

The CHAIRMAN. Great. That is great to hear.

Committee members will have until Friday, April 7th, to submit questions for the record.

Senator Casey, do you have any closing words you would like to say?

Senator CASEY. Madam Chair, thank you for calling the hearing, again, and also we know why she is Madam Chair now. We are

grateful for that bipartisan mission that she just gave us. So I am in, too, if it was not clear.

I want to thank the members of the audience who are here and so many others who were here for a good part of this hearing today. Phyllis, we are grateful you are here, and both doctors, Dr. Callahan and Dr. Yaffe, and Maria Shriver.

I would say to the people in the audience, and so many millions like you across the country, I know you may not on some days feel like you are overcoming something, you are not winning. But in so many ways you are, and you have led in this part of your life a quietly triumphant life, and that is much to be proud of. And we are grateful you are willing to share those stories and that inspiration with us, because in addition to the obvious and central role played by funding, your work and your stories and your families' stories will help us win this battle.

God bless you, and thank you.

[Applause.]

The CHAIRMAN. Thank you all again. This concludes this hearing. [Whereupon, at 4:56 p.m., the Committee was adjourned.]

APPENDIX

Prepared Witness Statements

**Testimony of Maria Shriver, Mother, Journalist and Founder of the Women's
Alzheimer's Movement, Los Angeles, California**

Thank you Chairman Collins, Ranking Member Casey and members of the Committee for the opportunity to testify today on the importance of doing everything we can to prevent Alzheimer's and other dementias while also ensuring the best quality care for those living with the disease.

As some of you know, Alzheimer's is a deeply personal issue for me. As some of you know, I've been here before—eight years ago to be exact.

In March of 2009, I sat here and testified about how Alzheimer's had taken up residence in what had been my father's beautiful brain.

My Dad, Sargent Shriver, was an idealistic, intelligent, optimistic, and dedicated public servant. His mind was sharp—a beautifully-tuned instrument that left people in awe and inspired. He was an expert at sharing his passions with the general public, thought leaders, *and* lawmakers. He often came here to the Hill to advocate for increased funding for his beloved Peace Corps and all the War on Poverty programs he created, including Head Start, Vista, Job Corps, and Legal Services for the Poor.

He loved working this building, and he was *really* good at it. He knew every Senator and Congressman by name. If he were here today, he'd know everything about each one of you: about your careers, your interests, your politics, your families—and, yes, your soft spots.

So imagine how painful it was to watch when this walking encyclopedia of a man went from knowing every fact about *everything* that had ever happened . . . to *not* knowing what a spoon or a fork was, or even what *my* name was, let alone his own.

Two years after I testified, my father died of Alzheimer's disease—and now . . . I'm back. Back again to testify—back *again* to focus *your* brains on this killer ravaging brains *and* families across this country. We need to continue to raise the profile of Alzheimer's in order to make progress in ending this disease.

We know the facts—Alzheimer's is the most expensive disease in America. It is the sixth leading cause of death in the U.S. and the only one of the top ten without a means to prevent, cure or slow its progression. According to the Alzheimer's Association, an estimated 5.5 million Americans are currently living with Alzheimer's or another dementia and that number could rise to as many as 16 million Americans by 2050. Let me be clear: that means by mid-century, the number of people living with Alzheimer's in this country could nearly triple.

Every 66 seconds, another brain will develop Alzheimer's disease. And according to the Alzheimer's Association, two-thirds of those brains will belong to women. A woman in her early 60s is twice as likely to get Alzheimer's as she is to get breast cancer in her lifetime—and the statistics are even more alarming for women of color. African-American women are twice as likely to get Alzheimer's as Caucasian women, and Latinas 1.5 times more likely. That's why I

founded the Women's Alzheimer's Movement—I believe that determining why women are more affected by Alzheimer's will help us unlock some of the mysteries of this disease. Instead of focusing only on the formation of plaques and tangles in the brain, let's also start focusing on women's brains and on their bodies—on chromosomes and hormones and inflammation.

We know what we need to do to fight this national crisis—we must continue to prioritize investments in scientific research to find a disease modifying treatment and one day, a cure. We must focus on ways to prevent and delay the onset of this fatal disease by living healthier lives. We must support caregivers of those living with Alzheimer's and provide them with the resources they need to provide care for their loved ones. And we must ensure there is a well-trained workforce ready to provide quality care to the increasing number of people living with Alzheimer's and other dementias who will need these services.

The stakes are high, and that is exactly why I want to continue to add my voice to the fight. I last testified on the importance of Alzheimer's before this Committee in 2009. I spoke about the importance of making Alzheimer's a national issue. As I stated then, if we do not prioritize Alzheimer's, Alzheimer's will not only devour our memories, but it will cripple our families, devastate our healthcare system and decimate the legacy of our generation. Well, you and other members of Congress from both sides of the aisle listened. Since 2009, we have seen great progress in the fight to end Alzheimer's—but our work is not done.

At the end of the 111th Congress, both the House and Senate unanimously passed bipartisan legislation, which requires the creation of an annually-updated strategic plan to address Alzheimer's. First released in May 2012 by the Secretary of Health and Human Services (HHS), the *National Plan to Address Alzheimer's Disease* (the National Plan) is structured to help those with the disease and their families today and to change the trajectory of the disease for the future. The National Plan outlines priority actions to reduce the financial impact of Alzheimer's; improve health outcomes for all Americans living with Alzheimer's; and improve prevention, diagnosis, treatment, and care, of individuals living with Alzheimer's and their caregivers. The National Plan's primary research goal is to effectively treat and prevent Alzheimer's by 2025. Unless there are resources to implement the plan and the will to abide by it, however, we cannot hope to make adequate progress.

Recognizing this challenge, Congress passed another bipartisan bill requiring the NIH to develop a professional judgment budget focused on achieving the milestones established by the National Plan, providing Congress with an account of the resources that NIH believes are needed to reach that primary research goal of treating and preventing Alzheimer's by 2025.

Having a National Plan and a clear path for the researchers working on promising breakthroughs to tell Congress what they need to make progress on Alzheimer's has led to great progress in increasing the federal commitment to Alzheimer's research. When I last testified before this Committee, Alzheimer's research was funded at less than \$450 million per year at the NIH. Today, Alzheimer's research receives \$991 million annually and is poised to grow even further. Congress has more than doubled its commitment to fight this disease, laying the foundation for more meaningful progress.

I want to thank Chairman Collins for introducing a bipartisan resolution declaring that achieving the primary goal of the National Plan to prevent and effectively treat Alzheimer's disease by 2025 is an urgent national priority. I strongly agree with that statement and with the resolution's call for robust investments in Alzheimer's research funding. I know millions of families around the country feel the same way.

In order to achieve this urgent national priority, we need to ensure the scientists have the funding they requested in the professional judgment budget—we cannot afford to stall research and delay this important lifesaving work. 1,300 Alzheimer's Association advocates are in Washington today to urge their members of Congress to support a \$414 million increase for Alzheimer's research funding for Fiscal Year 2018. This request echoes your call for increasing research funding and directly matches the professional judgment budget released by the scientists at NIH. I urge Congress to listen to these experts and fully fund that request—because doing so will empower the brilliant scientists like the ones I've met in laboratories around the country to discover the treatments to slow the progression of Alzheimer's and even prevent it from happening in the first place.

Funding research is critical to ending the Alzheimer's crisis, but we also need to ensure that the more than 5 million Americans living with Alzheimer's today have access to high-quality care and that their nearly 16 million unpaid caregivers have the support they need. That means we need to have an adequate, well-trained workforce and programs like respite, home health, and palliative and hospice care, to address the wide range of needs that come with the disease.

Finally, I have dedicated so much of my work to educating women about Alzheimer's because women are disproportionately impacted by this disease. The Women's Alzheimer's Movement believes that by answering the question of why women are more affected by Alzheimer's, we will unlock the other mysteries surrounding this mind-blowing disease and that will lead to a cure for all.

There is also growing body of evidence that a healthy lifestyle can delay, slow, or even prevent Alzheimer's and other dementias. We need to educate people on the connection between brain health and a healthy diet, physical activity, stress reduction, and how to expand brain power with life-long learning and social connection. The Women's Alzheimer's Movement is working to help women understand this connection. By promoting the positive effects of a variety of healthy lifestyle choices can have on brain health and overall well-being, we are empowering a new generation to combat this disease.

Nearly everyone knows someone or has been personally impacted by Alzheimer's. That is why I choose to speak up about this—for my father and for the millions of Americans currently struggling through this disease. I call on you to continue to make Alzheimer's the national priority it needs to be. Together, I am confident that we can make progress to one day end Alzheimer's.

**Kristine Yaffe, M.D., Scola Endowed Chair and Vice Chair, Professor,
Department of Psychiatry, Neurology, Epidemiology, Weill Institute of
Neurosciences, University of California, San Francisco, and Chief,
Neuropsychiatry, San Francisco, VA Medical Center, San Francisco**

Thank you Chairman Collins, Ranking Member Casey and members of the Committee for the opportunity to testify today before the Committee about one of the most important issues of our time, Alzheimer disease. My name is Kristine Yaffe, M.D. and I am Professor of Psychiatry, Neurology and Epidemiology at the University of California, San Francisco. I am also a physician and Chief of Neuropsychiatry at the San Francisco VA Medical Center and am a member of the Medical and Scientific Advisory Committee of the Alzheimer's Association.

Alzheimer disease is a brain disease and the most common form of dementia, a syndrome of cognitive changes usually associated with aging. Alzheimer's results in memory and other cognitive symptoms from a complex accumulation of abnormal proteins (including beta-amyloid and tau) in the brain that in turn leads to death of neurons. Despite tremendous advances in fundamental brain science over the past few decades, there is still much to learn about this process. It is unclear why some people get the disease and others, who have may have evidence of the protein accumulation, may not. Furthermore, despite great effort, we still do not have very effective treatments.

What we do know for sure is that Alzheimer disease is devastating. It carries tremendous toll on the patient, caregiver, our health care system and society. Alzheimer disease is also the sixth leading cause of death. We also know that because our society is aging and Alzheimer's is an age-related disease, it will grow exponentially and with that, the cost and burden will skyrocket. Even now, Alzheimer's has grown to become the most expensive disease in America with more than two thirds of this cost paid by Medicare and Medicaid. By 2050, the number with Alzheimer's are expected to triple, and the associated costs will quadruple to \$1.1 trillion per year unless we can change this trajectory through the development of effective treatments and prevention.

One of the most important conceptual changes in the field is that it takes decades for the abnormal proteins to accumulate in the brain before any clinical symptoms. Therefore, it may be possible to intervene early, even before symptoms, and prevent or delay Alzheimer disease. It is increasingly possible to identify those at higher risk based on genetics, early symptoms and detection of the protein accumulation. Thus, we are finally in a position to study if prevention is possible. This has evolved into two very important strategies (1) studies of risk factors that may be modifiable and (2) studies of new investigational drugs for people at risk but without symptoms.

There is emerging evidence that several factors may increase the likelihood of developing Alzheimer's in addition to genetics. Many of these risk factors may be "modifiable" and good targets for both individual and public health strategies.

One of the things we have learned is "what is good for the heart is good for the brain." The reason for this is that traditional risk factors for heart disease including hypertension, diabetes, and high cholesterol, are also associated with about a 50% increased likelihood of developing Alzheimer disease and vascular type of dementia. The exact mechanisms still need to be worked out but most likely result from effects on the brain blood vessels as well as greater amyloid accumulation. There are several trials underway assessing if certain diabetes and cholesterol medications and blood pressure control may protect against developing cognitive impairment. We need more research to understand how treatment of cardiovascular factors may benefit brain health. It is also key to understand when is the best life stage to address these cardiovascular factors with some evidence supporting that mid-life or even earlier is the best time to intervene.

The concept of cognitive reserve has been proposed as an explanation for why some people are able to tolerate the brain changes associated with Alzheimer's and other dementias without exhibiting symptoms. Animal studies indicate that certain factors inhibit or promote the brain's capacity to generate new neurons, even in adulthood, and that this "plasticity" of the brain underlies cognitive reserve. This is a very exciting concept as it suggests that there may be strategies, even in late life, to promote resistance to Alzheimer disease. Factors that contribute to cognitive reserve include physical activity and cognitive stimulation and education. Several studies, both observational and trials, support this idea that being more "active" both in body and mind, may prevent cognitive aging and Alzheimer's. More work is needed to test this strategy and make definitive conclusions for prevention.

Traumatic brain injury (TBI) is a common condition that peaks in early adulthood and again in late life. Many studies have reported that moderate and severe brain injury increases the risk of dementia; however, the mechanisms for this still need to be worked out. Recently there has been great interest in mild TBI (often called concussion) but there are only a few studies of mild TBI and risk of dementia and the results are controversial. This is a very important area for investigation given how common TBI is and how it can affect people across all ages.

An area of recent discovery has been the connection between sleep quality and risk of Alzheimer disease. This is a fascinating area of investigation as research suggests that during sleep, especially if adequate, proteins are "cleared out" of the brain. Therefore if sleep is disrupted due to sleep apnea or insomnia, the proteins such as amyloid may accumulate and lead to greater chance of Alzheimer's. Few studies have investigated if better treatment of sleep disorders might improve cognition and even delay Alzheimer disease but many are interested in exploring this line of investigation.

Many people want to know about diet and if certain diets may prevent Alzheimer's. There is still a lot we do not understand but it seems unlikely that individual vitamins, nutrients or foods are related to brain health unless someone is deficient in that substance. More compelling has been the idea that a dietary pattern, such as the Mediterranean diet (rich in vegetables, fruit, fish, nuts, olive oil), may be advantageous to both heart and brain health but studies have not been conclusive.

Some argue that these modifiable risk factors will not ever "cure" Alzheimer's disease. For that it is clear we need better drugs. However, because these lifestyle factors are so common and can be changed (without side effects), they could have a big effect on both the individual and society. Studies suggest if people could reduce these risk factors by a modest amount (for example do 10–25 percent more physical activity or lower hypertension by 10–25 percent), we could see a big effect on the downstream number of people that develop Alzheimer's over time. Furthermore, we need to study these factors in combination. Many countries have conducted multidomain trials in which several of these factors are addressed in combination and preliminary results look promising. It would be very important to conduct such trials in the U.S.

There has also been tremendous interest in developing more effective drugs for Alzheimer's and seeing if these may prevent the disease. In the US, there are four ongoing pharmacological trials testing possible prevention of Alzheimer's for people at risk for the disease (genetic risk or evidence of amyloid build up) but without any symptoms: the Dominantly Inherited Alzheimer Network Trials Unit trial, the Alzheimer's Prevention Initiative, Autosomal Dominant Alzheimer's Disease trial, and the Anti-Amyloid Treatment in Asymptomatic Alzheimer's Study. These trials are critical in order to identify better treatments as early in the disease course as possible. Most of them target the accumulation of the abnormal proteins. In this way, it may be possible to prevent or delay the disease. Many are optimistic that this approach will be high yield.

Some experts, including myself, think that someday, Alzheimer's will be like chronic heart disease with several available drugs that treat different aspects of the disease. It will not be the devastating diagnosis it is today but something that can be effectively slowed and treated. In addition, these drugs will be combined with lifestyle modifications such as cardiovascular health, physical activity and cognitive stimulation. Clearly in order to achieve this, we need more research. While the field has come a remarkably long way from when (just a few decades ago) dementia was considered a normal part of aging, we have a long way to go in order to effectively treat and prevent Alzheimer's.

In 2011, the bipartisan National Alzheimer's Project Act, that you Chairman Collins co-authored, became law requiring the creation of a National Alzheimer's Plan. The U.S. Department of Health and Human Services released this plan in 2012 with the

main goal to prevent and effectively treat Alzheimer's by 2025. In 2014, Congress enacted the Alzheimer's Accountability Act that requires the National Institutes of Health (NIH) to prepare for Congress and the President an annual professional judgment budget or bypass budget. In the bypass budget for Fiscal Year 2018, NIH Director Francis Collins has stated that the NIH will require an additional \$414 million in funding to remain on track to achieve the Plan's 2025 goal. I urge you to act in order to make this happen.

Thank you for your interest and time and all that you do.

Testimony of Christopher M. Callahan, M.D., MACP, Cornelius and Yvonne Pettinga Professor in Aging Research, Director, Indiana University Center for Aging Research, Scientist, Regenstrief Institute, Inc., Director, Eskenazi Office of Applied Research, Indianapolis, Indiana

Assuring Quality Care for Persons Living with Alzheimer's Disease

Introduction

Care can go terribly wrong for people with Alzheimer's disease. Imagine your elderly widowed mother at the age of 76 who appears to enjoy wonderful health. Maybe you've noticed some things, maybe an accident in the kitchen or in the car, maybe you noticed her repeating stories, but she seems happy and maintains a clean home. You keep your concerns to yourself. Then you get a call from the neighbor that your mom walked into the wrong home last night and was rude and disheveled. As you investigate further, you find that your mother's finances are a shambles. Her bank accounts have been drained by a heartless scammer. She has overdue utility bills. You take her to visit with her physician who admits he saw the signs but he didn't want to break her spirit when nothing can be done for this disease. He says she never mentioned she had children. Later that year, she falls and fractures her hip. She seems to ping-pong between the hospital and the nursing home for years with a dizzying array of medicines and doctors. You feel completely alone.

Stories like this will be played out multiple times per day over the coming years. Many families can tell a story much worse and more tragic. It doesn't have to be this way. Alzheimer's is a terrible disease—even without a cure, however, much can be done and we know how to do it. To make the journey of Alzheimer's disease less painful and costly, we all must do better. This includes patients, families, providers, communities, and policy-makers.

When we look at the key features of good care for failing brains, the very first thing we need is an early and accurate diagnosis. Many things can look like Alzheimer's disease and it is easy to dismiss early signs. A failing brain is not normal aging. Once a patient receives a diagnosis of Alzheimer's disease or a related dementia, a complex road lies ahead in terms of education, decision-making, treatments, and care planning. People need to know their new vulnerabilities and the services and supports available to them. But roadmaps exist. Research on models of care funded by the VA, NIH, AHRQ, the John A. Hartford Foundation, and CMMI show that we can decrease caregiver burden, improve patient outcomes, reduce burdensome care, and perhaps even decrease costs. These models integrate the health care team with community and social support services. The most ambitious of these models seeks to change the entire community response to Alzheimer's disease.[1]

Unfortunately, these new models fail to reach the millions of Americans who could benefit. None of these models is available to the typical American. Older adults living in rural America often find themselves hundreds of miles away from even basic services. This is true because these new models of care require significant effort to deploy.[2] Recently, the Center for Medicare and Medicaid Innovations (CMMI) funded programs to help primary care providers transform their practices to adopt such new models of care. Every person with Alzheimer's and every family caregiver will tell you that these efforts are welcomed, but they do not match the scale of the problem.

One difficulty in bringing these hopeful models of care to scale is an inadequate workforce. We've known for decades that the United States' production of physicians with special training in geriatric medicine and related fields lags far behind the need. For this reason, new models seek to expand the reach of this limited professional workforce. These strategies might include training nurses, social workers, or other professionals to provide the needed services or to serve as key members of team-based care. However, this workforce of medical professionals also falls short of the need as documented in several recent reports from the Institute of Medicine.[3, 4] In addition, our country needs a very large increase in the number of direct care workers who provide the hands-on care for older adults with Alzheimer's disease in the home and in nursing homes. In planning for the growing number of older adults with dementia, we need more physicians, nurses, social workers, direct care workers, and other paid professionals with special training in dementia care. However, if there is one reality that I could best highlight, it would be this: family caregivers are the hands, backbone, and hearts of the nation's workforce for Alzheimer's disease. This will not change in the coming 25 years as the number of Americans with dementia doubles. Family caregivers will sacrifice their sleep, their health, their finances, their careers, and their friends to provide care for their loved one in the home for as long as possible. They will provide this difficult care, but they shouldn't have to do it alone. So often, we hear family caregivers say at the end of their draining 10-year journey that they wish they knew then what they know now. If we hope to assure quality care for persons living with Alzheimer's, then we need to better support their family caregivers. New models of care show that this is possible.

A Better Way to Care for Persons Living with Alzheimer's Disease

There are many examples of research studies that demonstrate improved care for persons living with Alzheimer's disease. Recent publications provide a more extensive review of the history, design, and components of these interventions.[5-7]. A summary of current clinical practice guidelines for Alzheimer disease suggests that comprehensive dementia care should include, for example:[2]

1. Case-find for cognitive impairment coupled with a second stage assessment to diagnose dementia
2. Evaluate for treatable conditions contributing to cognitive impairment
3. Evaluate for remediable causes of excess disability due to treatable impairments
4. Disclose the diagnosis, prognosis, and treatment options to the patient and family
5. Refer patient and caregiver to community support agencies, such as the local Alzheimer's Association
6. Encourage and facilitate patient's continued physical, social, and mental activity
7. Consider specialty referral for patients with unclear diagnosis
8. Assess and treat depression and other behavioral and psychological symptoms of dementia with an emphasis on non-pharmacologic approaches
9. Consider the risks and benefits of all medications, including anti-dementia drugs
10. Facilitate communication among the care providers both within the health care system and the community
11. Discuss home safety, driving, potential for financial abuse, and advanced care planning
12. Support the family caregiver as a key member of the health care team

Four exemplar studies, among many others, provide examples of how these guidelines might be put into practice.[2] One of the first such studies, the "Family Intervention to Delay Nursing Home Placement in Patients with Alzheimer's Study" focused on spouse-caregivers.[8, 9] The intervention

sought to organize more support from other family members and across the entire journey of the disease. The program included tailored individual and family counseling, participation in support groups, and telephone counseling. This support delayed nursing home placement by 1.5 years. In another study called "Resources for Enhancing Alzheimer's Caregiver's Health" (REACH), researchers were able to reduce the burden of caregiving and improve caregivers' emotional health through education and support that also reduced the time burdens of caregiving.[10] REACH interventions have now been adapted and adopted in multiple different settings, including the VA.[11] In a third study, investigators used a population-based approach that emphasized linkages with community resources and multi-agency coordination, including coordination with primary care providers.[12] Patients were identified through their diagnosis in electronic records and provided an intervention that included a professional care manager, internet-based care protocols, and tools to collaborate with the family caregivers in developing care plans. The intervention improved the quality of care, improved patients' and caregivers' access to existing community services, and improved the quality of caregiving and social support. In a fourth study, a collaborative care model focused within the primary care setting sought to improve the outcomes of care for both the patient and the family caregiver.[13] A nurse practitioner led the care management team and focused on non-drug strategies to manage the behavioral symptoms of dementia. Aided by the medical care team and by web-based tracking of symptoms, the nurse practitioner and family caregiver were able to reduce the burden of behavioral symptoms for the patient and the caregiver.

Unfortunately, the typical American family living with dementia would not find these models of care available in their communities.[14] Providers and health care systems judge these programs difficult to implement in a typical clinical practice. The models require substantial redesign of the clinical practice including changing the roles and types of providers that comprise the team-based approach. As already noted, these team members are not widely available in the workforce.[3] These approaches also require a robust and high-tech communications infrastructure to coordinate care across health care providers, community service agencies, and family caregivers. This communications infrastructure is unavailable to most clinical practices. Finally, most primary care physicians provide care to fewer than 50 persons with dementia and they face competing priorities in providing care for many other complex chronic medical conditions.[15] Because these models of care and their requisite workforce are unavailable, persons living with dementia and their family caregivers face a fragmented health care system and a patchwork community services that seems to be hopelessly ineffective. Recent publications from the Institute of Medicine describe the burden of family caregiving and other workforce limitations.[3, 4, 16, 17] Caregivers suffer from extreme emotional and physical stressors as well as economic stressors.[17] Caregivers, who are most often women, sacrifice personal income to provide care in the home and spend more out of pocket than caregivers for other diseases.[18]

As researchers, providers and policy makers seek to plan for the future, three assumptions greatly limit the potential choices to assure care across the long arc of Alzheimer's disease. First, the number of older adults with dementia will double in the next 20 years. Second, technology will not save us from needing to provide hands-on care for persons with Alzheimer's disease. Third, family caregivers will provide the majority of hands-on care. Medicare beneficiaries with dementia live about 90% of their last five years of life at home, receiving care from family and paid (out of pocket) caregivers while consuming ambulatory health care services largely paid for by Medicare. However, 40% of health care payments by Medicare and Medicaid support the 10% of care days provided to persons with dementia

in hospitals and nursing homes.[19] Among persons with dementia, research suggests that we are spending money on care that may be ineffective and unwanted.[20, 21] Recent projects supported through the Center for Medicare and Medicaid Innovation (CMMI) build from prior research (such as the four clinical trials described above) to explore whether care could be improved for patients and their families by redesigning care and reallocating health care dollars away from high-cost settings. Three CMMI-supported projects are briefly described below.

The Indiana University Aging Brain Care Program

With support from CMMI, Indiana University implemented the Aging Brain Care (ABC) program.[22] The project included partners from the Regenstrief Institute, Inc., and Eskenazi Health in Indianapolis. The partner organizations developed a population-based electronic medical record (eMR-ABC) and designed the program to be primarily based on care in patients' homes.[23] The project also developed a new workforce of care coordinator assistants who had a minimum of a high-school diploma and were given special training to care for older adults with dementia.[24] The care coordinator assistants were supported by a nurse and social work team who are themselves supported by a geriatric medicine physician. This expanded team is supported by the eMR-ABC which was specifically designed to support population and patient-level tracking, decision-support, and to monitor the patient's transitions across sites of care. The team worked with patients, families, primary care providers, and specialists to develop patient-specific care plans, deliver evidence-based protocols, and respond to real-time monitoring and feedback.[25]

Over 36 months, the program reached more than 3,000 patients with either dementia or late life depression receiving care from 8 primary care clinics in Indianapolis (Urban) and five primary care clinics in Lafayette (rural). Within the first 12 months, at least 90% of the informal caregivers of patients had no evidence of clinically relevant caregiver burden and at least 60% of the patients had no clinically relevant behavioral and psychological symptoms. Informal caregivers reported more stress relief and improved communication among patients, caregivers, and their providers. Patients and informal caregivers also developed better coping mechanisms. Although the official findings of the independent evaluator are still in progress, preliminary findings suggest no clear trends for cost of care. The ABC Program has been sustained beyond the evaluation period. It is a flagship program for Eskenazi Health's new Center for Brain Care Innovation in Indianapolis. Indiana University also licensed the ABC model and the eMR-ABC case management software to Preferred Population Health Management to better assure its wider distribution.

The UCLA Alzheimer's and Dementia Care Program

The UCLA Alzheimer's and Dementia Care (ADC) program supported by CMMI was launched in November 2011.[26] The program is based at an academic health care system and partners with community-based organizations to provide comprehensive, coordinated, patient-centered care for patients with Alzheimer's disease and other dementias. Unlike the Indiana project, the UCLA program focused exclusively on persons with dementia. The goals of the program are to maximize patient function, independence and dignity, minimize caregiver strain and burnout and reduce unnecessary costs through improved care. The UCLA ADC program was developed based on theory and evidence for enabling, empowering, and supporting caregivers,[27, 28] as well as providing disease management/care

coordination to navigate the complicated health care system[12, 13] with the goal of achieving the 'triple aim' of improving the experience of care, improving the health of populations, and reducing health care costs.[29]

The program, which has now provided care to over 2000 patients and their family members, uses a co-management model (nurse practitioner Dementia Care Manager) and consists of five key components:

- patient recruitment
- structured needs assessments of patients and their caregivers
- creation and implementation of individualized dementia care plans based on needs assessments
- monitoring and revising care plans, as needed, and
- access 24/7, 365 days a year for assistance and advice

Because many of the services that patients with dementia and their caregivers need are provided by community-based organizations, the program created a menu of services provided by each of the 8 partnering community-based organizations that the DCMs can use to provide referrals for specific services and a voucher system so that community-based organizations will receive payment for services provided. Details about each of these components have been published in peer-reviewed journals and a book chapter.[26, 30, 31]

The program has addressed unmet needs. Prior to the program, caregivers were uninformed and fighting this battle alone. Only 38% knew where to turn to get answers about dementia problems and only 24% felt that they had a healthcare professional to help them work through dementia issues. At baseline, 13% of caregivers were depressed and 33% had high stress; those reporting higher levels of stress were more likely to be female, reported more depressive symptoms and cared for more functionally impaired patients with more behavioral symptoms.[32]

After entering the program, 94% of caregivers felt that their role was supported and 92% would recommend the program to others. At one year, they reported receiving significantly more advice about dementia care and had significantly higher self-efficacy about managing the disease. Their confidence in handling problems and complications of Alzheimer's disease and dementia improved by 79%. A sample quote from a grateful caregiver included: *"The program has turned my life around. I now have a grip on things. I do not feel totally overwhelmed. I have been given some counseling and adult day care... I can honestly say she has sort of saved me."*

As a result of this program, at one year, despite disease progression, patients' behavioral symptoms improved by 12% and depressive symptoms were reduced by 24%. In addition, at 1 year, caregiver depression scores, distress related to behavioral symptoms, and caregiver strain improved by 25%, 24%, and 11%, respectively. The program's external evaluator has not yet released the program's final results. However, preliminary findings are encouraging for overall reductions in preventable acute care use and total costs.

The Optimizing Patient Transfers, Impacting Medical Quality, and Improving Symptoms: Transforming Institutional Care (OPTIMISTIC) Program

A third project funded by CMMI and conducted in collaboration with the Medicare-Medicaid Coordination Office was also based at Indiana University and included multiple regional partner organizations seeking to improve care for older adults in nursing homes.[33] The project targeted long-stay residents, most of whom suffer from dementia, in 19 central Indiana nursing facilities. The intervention combined lessons learned in collaborative care, care transitions, and palliative care to support nursing facilities in reducing avoidable hospitalizations. Not all hospitalizations are avoidable; some older adults with dementia whether at home or in nursing homes require hospitalization. Potentially avoidable hospitalizations are those that could be avoided with improved care or care more in accordance with the patient and family goals of care. The program invested in additional on-site direct care services and supports and delivers practical resources to help facilities manage cultural change and support ongoing education and training of staff. This support is accomplished through a registered nurse hired through the resources of the program and assigned to individual facilities. This project nurse is supported by advanced practice nurses who span several facilities but who are available to respond to urgent care needs beyond the scope of practice of the registered nurse. This team is further assisted by geriatric medicine physicians. Evidence-based interventions, which comprise the foundation of the project, have three major components: (a) improved medical care at the facility; (b) transitional care; and (c) palliative care. The innovative nature of the project stems from its integration of these components, the shift from reactive care to proactive care, and the goal to change the culture of the nursing home environment to a learning organization.

The medical care component is adapted, in part, from the INTERACT model, and provides tools to allow facility staff to recognize and initiate early care for a change in resident status.[34] Although the goal of the project is to reduce transitions, some transitions are appropriate. The intervention seeks to better manage these transitions through an enhanced exchange of information and building relationships between the facility and the emergency departments and hospitals where residents receive care, including nursing facility staff access to a regional health information exchange. Information exchange is vital for transitions of residents with dementia who often cannot articulate their needs. The palliative care component is derived from the Physician Orders for Life Sustaining Treatment (POLST) program.[35] POLST overcomes the limitations of traditional living wills and code-status only orders by converting treatment preferences into immediately actionable medical orders that transfer across settings of care. The palliative care program also trains and engages nursing home staff in advanced care planning and supports education for both residents and their families in palliative and hospice care.[36] Importantly, this program requires collaboration between multiple stakeholder groups including the academic project team, a diverse network of nursing facilities, community physicians, and State and Federal Government.

An independent evaluation of this project was recently published in *Health Affairs* in March 2017.[37] The independent evaluator reported that the Indiana intervention resulted in a reduction in all-cause hospitalizations and a reduction in potentially avoidable hospitalizations. These reductions in hospitalizations were associated with a reduction in Medicare costs. Thus, we have evidence that we can improve quality and outcome of care at an affordable cost.

Summary

In 2017, it is not acceptable to suggest that nothing can be done to assure quality care and improve outcomes for persons living with dementia and their families. The studies described here represent only a small percentage of hundreds of studies conducted over five decades of research. It is also no longer acceptable to say that these studies are limited to impractical academic exercises. We now have evidence that these interventions can be practically implemented. These studies show we can do much better. In 2017, the question is not whether we have programs to assure quality care, the question is how we take these programs to scale so that they are available to all American families struggling with Alzheimer's disease. In the opening paragraph of this testimony, I asked that you imagine the frustrating care that so many American families currently endure. Imagine instead your own care as an older adult with a failing brain just 10-20 years from now- or maybe even next year. Imagine that you and your child, recognizing how much can be offered for a person with cognitive impairment, seek an early evaluation. Imagine that your provider's office is now fully resourced to provide team-based care, including access to collaborative care programs and community-based resources and home-based supports. Imagine your community has been redesigned to promote aging in place. Imagine that your goals of care are honored and that your spouse or child is duly recognized as part of your care team. Imagine that you are able to stay in your home until your last days with support services for you and your family. We know now that this future is possible. We are designing this future not only for our parents, but for ourselves and for our children.

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**Testimony of Phyllis Gallagher, Family Caregiver,
Frackville, Pennsylvania**

Thank you Chairman Collins, Ranking Member Casey and members of the Committee for the opportunity to testify today on the toll of Alzheimer's and other dementias. As a caregiver for my husband John, I hope my story will shed some light on the reality of this cruel disease.

My husband John and I have been happily married since 1993—and I do mean happily. John is the nicest, kindest man. We had fun together. Prior to his diagnosis, John was healthy as a horse. He was 6'2" and 260 pounds and went to the gym every day. He ate well, though he is a good Irishman and did enjoy a beer here or there. John worked in the Pennsylvania State Capitol in a job he enjoyed. He was social and was living a full life.

After his father passed away in 2008, I started to notice that John was having a harder time finding his words. As we would later learn, this was the start of our journey with Alzheimer's. John was only 49 years old at the time.

We started with our primary care doctor, who thought John might be suffering from a stroke, or depression and anxiety following his father's death. When John did not get better, we went back to the primary care doctor 6 months later, which was then followed by a visit to a local neurologist. We had no new answers, and months went by as John continued to struggle with his speech and was showing more erratic behaviors. He wasn't himself, he behaved irrationally. John was physically healthy—it was his brain that wasn't.

After months and months of unanswered questions and new combinations of medications to address the symptoms, John started seeing a psychiatrist.

The psychiatrist was the first one to suggest that these symptoms could be memory-related. I tried to get John in to see a specialist at several facilities in Pennsylvania but each place had a 6-month wait. The Memory and Alzheimer's Treatment Center at Johns Hopkins only had a 3-month wait to see someone, so that's where we went. If there were more trained specialists in this field, we might not have had to wait so long or travel as far to see someone.

After our 3-month wait, John and I made the first of what would be many drives from our home in Frackville, Pennsylvania, to Baltimore, Maryland, for John to have a full neurological work-up at Johns Hopkins. The team at Hopkins wanted to use a PET scan as part of their diagnostic process, but unfortunately, it was not covered by our insurance. After a wave of testing, John was officially diagnosed with Alzheimer's disease.

John retired from his job in March 2012, and we decided to do what we could to help the next person going through this disease. It was extremely important to both of us that we not be

complacent—we had to do something. We got involved with our local Alzheimer’s Association chapter and walked together in the Walk to End Alzheimer’s. John participated in several research projects at Hopkins and in one of them was finally able to get that PET scan. He also decided that he wanted to donate his brain to research after he dies. As John put it, “They might not be able to help me, but what if my girls get it?”

We also decided to live our lives fully while John still could. We went to Ireland for the big “bucket list” trip. We went out a lot with friends. If he wanted to go to lunch at the same place every day, we did. We made regular trips to New York to see his daughter. I did anything to make him happy in the course of this, and we had as much fun as we could.

That does not mean we did not face our share of challenges. As time went on, John always needed supervision. If I needed to take a shower, I would have a neighbor come over to watch him. I would do things around the house at night while he was sleeping. The first time you have to help your spouse in the bathroom is traumatic. People don’t tell you about that.

Because of his age, John was not eligible for many programs available to people with Alzheimer’s. Many of these programs are only for people over the age of 60. Or they are aimed at people with physical disabilities; I could get help if he’d lost a limb, but not because he has dementia. If you can’t find someone to help you, you’re stuck. I was able to get John into an adult day program 2–3 afternoons per week. What a relief that was—I could go grocery shopping or run other errands without worrying about John.

The difficulty that came with communication was a surprise. When he couldn’t find his words or had trouble speaking, we had to communicate through what I came to call the “Charades of the Gallagher’s.” We had as much fun as we could in such dire circumstances.

After John’s diagnosis, we talked a lot about what he wanted as the disease progressed. We talked about the likelihood of John needing to be in a nursing home one day and planned his funeral. I remortgaged our house, hoping to care for him at home as long as I could. We renovated our first floor to include a full bath and laundry room to make the home handicap accessible to anticipate his future needs.

Today, John is now in a nursing home. Medicaid helps to cover the cost, but I still pay \$1,850 out of pocket each month. That means that I don’t go out unless a friend can pay for me. I work with a limited grocery budget, and I rarely can afford to go to the movies. I participate in activities that don’t cost money so that the resources I do have can go to my husband’s care.

When someone has Alzheimer’s, it’s not just the person who gets sick—it’s the whole family. This disease takes a toll on a community of people.

Without our friends, family and neighbors, I would not have been able to care for John.

John and I believe that you can't just sit around go "boo-hoo." You have to do something. That's why I wanted to be here today and why I participated in the Alzheimer's Association Advocacy Forum for the first time this year.

This week, I joined 1,300 advocates from across the country to make a difference here in Washington. We are here to speak on behalf of the 5.5 million Americans living with Alzheimer's today, to advocate for their care, and to fight for more research funding. Alzheimer's is a fatal disease with no means to prevent, cure or even slow its progression. Investing in research is the only way to change that.

Alzheimer's research is currently funded at \$991 million annually, but the scientists at the National Institutes of Health (NIH) say they need more to make progress toward ending this disease. Researchers at the NIH asked for an additional \$414 million for Fiscal Year 2018. As a caregiver and advocate, I am respectfully asking Congress to fulfill that request.

Today, John is 58 and in the end stages of Alzheimer's. This disease has ravaged our family, but that doesn't mean we have given up hope.

Something positive has to come out of this. It's inspiring to be here on Capitol Hill for the first time with so many others just like me. We all are counting on you to take action so we can, once and for all, end Alzheimer's.

Additional Statements for the Record



SENATE SPECIAL COMMITTEE ON AGING

**"The Arc of Alzheimer's: From Preventing Cognitive Decline in Americans to
Assuring Quality Care for Those Living with the Disease"**

March 29, 2017

Submitted for the Record

TESTIMONY OF THE ALZHEIMER'S FOUNDATION OF AMERICA

The Alzheimer's Foundation of America (AFA), a national nonprofit that unites more than 2,600 member organizations in the goal of providing optimal care and services to individuals living with dementia, and to their families and caregivers, is grateful that the United States Senate Special Committee on Aging is holding this hearing on *The Arc of Alzheimer's: From Preventing Cognitive Decline in Americans to Assuring Quality Care for Those Living with the Disease*. AFA offers the following testimony:

Alzheimer's Disease and Its Impact

Alzheimer's disease is the sixth leading cause of death in the US¹ and the only cause of death in the top 10 with no cure or treatment to slow its progression. It is an irreversible, progressive brain disease that slowly destroys memory and thinking skills, and eventually even the ability to carry out the simplest tasks. Currently, more than 5 million Americans are living with Alzheimer's disease and studies suggest that as our population ages, that number will nearly triple by 2050.² Individuals with Alzheimer's disease use a disproportionate amount of health care resources. For example, they are hospitalized two to three times more often than people the same age who do not have the disease.³ Similarly, nearly half of all nursing home residents have Alzheimer's disease.⁴

In 2012, the direct costs of caring for people with Alzheimer's disease or other dementias to American society was an estimated \$200 billion, including \$140 billion in costs to Medicare and Medicaid. These costs will soar to a projected \$1.1 trillion (in today's dollars) by 2050. This dramatic rise includes a 500 percent increase in combined Medicare and Medicaid spending.

Further, for each person with Alzheimer's disease there are multiple caregivers who respond, 24 hours a day, seven days a week, to needs associated with the most basic activities of daily living, including bathing, dressing, and using the toilet. Caregiving duties often fall on family members who are overwhelmed both emotionally and physically, and whose health and well-being often suffer as they fulfill this role.⁵ There is a higher incidence of sickness and mortality among Alzheimer's disease caregivers, compared to other caregivers.⁶ In 2011, family caregivers

¹ While the Centers for Disease Control and Prevention (CDC) lists Alzheimer's disease as the sixth leading cause of death in the US (see, www.cdc.gov/nchs/fastats/leading-causes-of-death.htm), recent studies cite that over 500,000 Americans a year die as a result of dementia, making Alzheimer's disease the third leading cause of death in the US. See, Contribution of Alzheimer disease to mortality in the United States, James, Bryan Ph.D. et. al., *Neurology* (March 5, 2014) (www.neurology.org/content/early/2014/03/05/WNL.0000000000000240).

² Alzheimer disease in the United States (2010–2050) estimated using the 2010 census, *Neurology* (March, 2013).

³ CAREGIVING COSTS: Declining Health in the Alzheimer's Caregiver as Dementia Increases in the Care Recipient, National Alliance for Caregiving, Nov, 2011 (www.caregiving.org/pdf/research/Alzheimers_Caregiving_Costs_Study_FINAL.pdf).

⁴ See, Comparison of Characteristics of Nursing Homes and Other Residential Long-Term Care Settings for People With Dementia, AHRQ Publication No. 12(13)-EHC127-EF (www.ncbi.nlm.nih.gov/pubmedhealth/PMH0050127/) (Approximately 45-67% of all nursing home residents have dementia).

⁵ CAREGIVING COSTS: Declining Health in the Alzheimer's Caregiver as Dementia Increases in the Care Recipient, National Alliance for Caregiving, Nov, 2011.

⁶ *Ibid.*

provided an estimated 17.4 billion hours of unpaid care, a contribution to the nation valued at over \$210 billion.⁷

Despite the need, federal investment in Alzheimer's disease research lags far behind resources allocated to other major diseases. In fiscal year (FY) 2016, the National Institute of Health (NIH) spent approximately \$910 million on Alzheimer's disease, while \$5.6 billion went to cancer research; \$3 billion for HIV/AIDS; \$2 billion for cardiovascular disease; \$1.3 billion for heart disease; and more than \$1 billion for diabetes. This chronic underinvestment for Alzheimer's disease research leaves promising research unfunded and slows scientific progress.

In recent years, there has been a growing recognition that there needs to be a robust federal response to the Alzheimer's crisis. In 2011, Congress passed the National Alzheimer's Project Act which established a national Alzheimer's plan with a goal of finding a cure or modifying treatment for Alzheimer's disease by 2025. In addition, the FY'16 federal budget contained a momentous 60 percent increase in Alzheimer's disease research at the National Institute on Aging (NIA), the main agency responsible for Alzheimer's disease research at NIH. With this increased appropriation, NIA spent approximately \$991 million for Alzheimer's research in FY'16.

Yet more needs to and must, be done. AFA hopes Congress will continue to build upon this progress and make combatting Alzheimer's disease a national priority by committing **\$2 billion for Alzheimer's disease research at the National Institutes of Health in FY'18**. Leading Alzheimer's disease scientists have called for \$2 billion in annual research funding to keep us on track to achieve the 2025 goal of the national plan. With just eight short years until the deadline, we can no longer wait. We need to ensure there is proper investment in promising research today that will get us to a cure tomorrow.

And until we can get to a cure, we need to ensure that the millions of American families confronting Alzheimer's disease have access to proper caregiver supports and services. Such services are vital and meaningful in helping caregivers cope with daily challenges of the disease. In addition, access to these services saves government resources by allowing people with Alzheimer's disease to have better health outcomes and delaying the need for placement in more costly institutional settings. To ensure access to these services meets growing needs, AFA calls for **an additional \$40 million to fund caregiver supports and services provided by programs administered by the Administration for Community Living (ACL)**. These programs, include Alzheimer's disease demonstration grants, case management, caregiver training and support under the Alzheimer's Disease Initiative.

Promoting Memory Screens and Brain Health

Memory screening and early Alzheimer's detection have been a hallmark of AFA's mission of providing optimal care and services to individuals living with dementia. AFA has long supported efforts that increase awareness of memory screening and its benefits, as demonstrated by its National Memory Screening Program which provides free, confidential memory screenings in convenient locations in communities across the nation. AFA's National Memory Screening

⁷ A.Stevens, PhD., *Next Steps in Family Caregiving Research: Interventions Designed for Impact* (www.nia.nih.gov/sites/default/files/alan_stevens_0.pdf).

Program also provides a valuable opportunity to learn more about healthy lifestyle choices for successful aging and brain health. For more on AFA's Memory Screening Program, please visit: www.nationalmemoryscreening.org.

A memory screening does not connote a diagnosis of any kind; however, a person who scores below the normal threshold will be referred to a clinician for a more comprehensive evaluation. While screening marks an enormous first step toward detection, people with memory problems need access to clinicians well trained in dementia to take the next step in the process and to avoid misdiagnosis and under-diagnosis.

It is also important that family members talk about brain health, especially if they notice a loved one having difficulty with memory. To help facilitate this discussion, AFA teamed up with the National Alliance for Caregiving (NAC) to develop a "Talk Brain Health" conversation kit to help family members hold constructive conversations, urge memory screenings and promote healthy brain activities. The campaign included several free educational webinars and social media outreach. Learn more at: www.caregiving.org/talkbrainhealth/.

AFA recommends the expansion of memory screening efforts. Federal and state health facilities can be utilized as screening sites, and CMS can promote screenings through outreach to its public health partners. Moreover, individuals who are ultimately diagnosed must have access to federal health programs for proper treatment and supportive services.

Some of AFA specific recommendations to promote brain health include:

- **Expanding memory screening efforts and promotion of the benefits of memory screening and early detection of Alzheimer's disease by the Centers for Medicare and Medicaid Services (CMS) and its partners, as well as providing individuals who are ultimately diagnosed with access to federal health programs for proper treatment and supportive services.**
- **Establishing regional Memory Evaluation and Treatment Centers through public-private partnerships that focus on developing, improving and disseminating best practices for clinical care for persons with Alzheimer's disease and their family caregivers.**
- **Promoting the Medicare Annual Wellness Visit as a vehicle for healthcare professionals and individuals to talk about memory problems and cognitive function.**

Living with Alzheimer's Disease

Currently, there are no consistently effective pharmaceutical interventions to stop or slow progression of Alzheimer's disease. As a result, some health professionals delay diagnosis because they feel they have nothing to offer the individual living with Alzheimer's disease. Yet, strides are being made to develop tools that more accurately detect and diagnosis Alzheimer's earlier in the disease's progression.

The benefits of early and proper detection of Alzheimer's disease are many and varied. Although there are no current treatments to cure, prevent or reverse the disease, or to change the

underlying disease process, available treatments—both pharmacological and non-pharmacological—can help slow progression of symptoms. The general rule of thumb is: the earlier, the better.

When diagnosed earlier in the progression of the disease, when cognitive function is intact, individuals with Alzheimer's disease can provide greater input into their own care planning. In addition, early and accurate diagnosis helps people with Alzheimer's disease and their families plan for the short- and long-term, including the ability to:

- inform family members, friends, and caregivers of their diagnosis;
- make living arrangements;
- address financial and legal matters;
- express end-of-life wishes;
- adopt healthy lifestyles (e.g., proper diet, mental activity, physical exercise);
- take advantage of caregiver training and support services; and
- develop care teams and other support networks.

Having a domino effect, this input helps relieve family caregivers of the burden of making these critical decisions for loved ones, which can mitigate the impact of Alzheimer's disease on the physical and mental well-being of caregivers and, as a result, reduce related health care costs.

Documentation of Alzheimer's disease in an individual's medical record is critical for care coordination and is necessary for health care providers to address complications in the management of other co-morbidities, such as diabetes. It will also help ease transitions between care settings and help identify individuals with dementia to hospital emergency departments and first responders. Given the projected skyrocketing cost of dementia care, these preventive measures, likewise, can result in cost savings to families, government and society.

Recognizing the importance of, and vital need for, care management services for the millions of Americans living with dementia, CMS recently established Medicare coverage for cognitive impairment care assessment and planning —for both the individual and his/her caregiver—following a dementia diagnosis.⁸

To ensure successful implementation of CMS' cognitive impairment care assessment code, AFA recommends that there be:

Provider Awareness of Care Management Benefit

CMS should conduct proactive outreach to the provider community, through seminars, webinars, social media and other methods, to promote awareness of the new code Medicare code that reimburses for care management for those with cognitive impairment to spur its utilization. Collaborative engagement by CMS with patient advocacy groups, professional medical societies

⁸ See, Medicare Physician Fee Schedule for Calendar Year 2017 (CMS-1654-P).

and industry trade organizations also is essential to achieve broader awareness and to ensure utilization of this important benefit.

Training in Dementia Care Planning

Proactive efforts will be necessary to help educate and train health care providers on best practices, strategic tools and resources for dementia care planning. CMS, in conjunction with professional medical societies, should offer educational seminars on dementia care management that will provide continuing education credits for medical professionals. In addition, care management for individuals with cognitive impairment should be incorporated as a metric when determining quality ratings for Medicare-participating health care providers.

Adequate Provider Reimbursement for Care Assessment and Planning

To ensure participation of providers, Medicare payment under the code also must be adequate to reimburse for the providers' time, expertise and training necessary to make meaningful care assessment and care planning recommendations.

Caregiver Involvement

AFA supports the active inclusion of persons living with dementia and their family caregivers at all points in the decision-making process. However, at a certain point in the disease's progression, the individual with dementia may not be able to be directly involved in making care decisions. In such cases, CMS should ensure that the care planning services still are discharged, as appropriate, to the Medicare beneficiary's family caregivers.

Access to Innovative Person-Centered Care Models

To enhance the impact of any care management program, CMS should expand access to innovative care models that provide better outcomes and lower costs for individuals with chronic conditions, including dementia.

Several of these person-centered, team-based care models for people with dementia currently are being evaluated by the Center for Medicare and Medicaid Innovation (CMMI) with promising results. Minnesota's ACT on Alzheimer's program, which coordinates dementia care training, supports and resources, has shown potential cost savings to help guide the investment of resources in the future.⁹ Additionally, CMS recently released data from the Independence at Home (IAH) demonstration, which provides individuals with chronic illness (including Alzheimer's disease) a complete range of primary care services in the home setting. The results indicated the demonstration has produced an average savings of \$1,010 per beneficiary enrolled in the 15 participating practices.¹⁰

⁹ See, *Estimating The Potential Cost Savings From The New York University Caregiver Intervention In Minnesota*, *Health Affairs*, April 2014 (<http://content.healthaffairs.org/content/33/4/596.abstract?ijkey=81Sa5vdZnrEvc&keytype=ref&siteid=healthaff>).

¹⁰ See CMS Press Release, *Independence at Home Demonstration Performance Year 2 Results* (August 9, 2016) (www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2016-Fact-sheets-items/2016-08-09.html).

These innovative care models need to be implemented nationally and provided as a care option for any Medicare beneficiary with dementia.

Lastly, **accurate and timely diagnosis can provide greater opportunities for people with Alzheimer's disease to participate in clinical trials.** New drug therapies currently being tested focus on stopping progression in the early stages of the disease, requiring trial participants to have be pre-symptomatic or with low to mild cognitive impairment. Greater participation in clinical trials is essential in order to accelerate drug development.

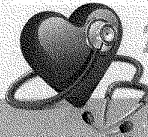
Conclusion

AFA applauds the Senate Special Committee on Aging for holding this hearing exploring the arc of Alzheimer's, promoting awareness of the disease and examining its impact on millions of American families. While currently there's no cure, AFA believes that positive steps can be taken by those with a diagnosis of Alzheimer's disease that can enhance their quality of life and delay placement in more costly institutional settings. Further, undergoing periodic memory screenings and paying attention to brain health can help prevent or delay cognitive decline. AFA looks forward to working with the Aging Committee and other champions in the Senate to call such policies, including those recommended in this testimony, which will help promote cognitive health and improve the lives of those living with dementia and their family caregivers.

BRAIN HEALTH

7 Tips for Successful Aging

1. Successful Aging Starts at a Young Age and Continues Through Old Age



2. CONTROL RISK FACTORS for Alzheimer's Disease

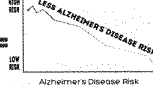
Diabetes • Obesity • Depression
Heart Disease • High Blood Pressure

3. THE EVIL THREE: POOR DIET, INACTIVITY, SMOKING

ELIMINATING:



80% LESS
Heart Disease
Stroke Type 2 Diabetes



Source: U.S. Centers for Disease Control and Prevention

4. GOOD FOR THE HEART GOOD FOR THE BRAIN

NOURISH

| Your Body | Your Mind | Your Soul |
|---|--|---|
| <ul style="list-style-type: none"> No Trench Potatoes Allowed Don't Smoke Don't Drink Alcohol Take Many Vitamins Limit Alcohol | <ul style="list-style-type: none"> Practice Mindfulness Practice Gratitude Practice Self-Compassion Practice Transcendental Meditation | <ul style="list-style-type: none"> Healthy Attitude Gratitude Forgiveness Spirituality/Religion Volunteering Manage Stress Laugh |

Say YES to:

- Colorful, Dark-Skinned Fruits/Vegetables
- Vitamin E Rich (i.e. blackberries, spinach)
- Beta-Carotene Rich (i.e. broccoli, sweet potato)
- Whole Grains
- Omega-3 Fatty Acids (i.e. salmon, sardines)
- Antioxidants (i.e. blueberries, walnuts)



Say NO to:

- Red Meats
- Red Foods
- Saturated Fats
- Highly Processed Foods
- Salt
- Added Sugars
- Trans Fatty Acids

6. SEE YOUR DOCTOR REGULARLY

- Medicare Preventive and Screening Benefits
- Cardiovascular Screenings
- Diabetes Screenings
- Depression Screenings
- Tabacco Use Cessation Counseling
- Medical Nutritional Therapy Services
- Detection of Cognitive Impairment

7. CAREGIVER CHECK-UP

Due to Behavioral/Cognitive Symptoms of a Loved One With Alzheimer's Disease, Caregivers Most Commonly:

| GIVE UP | SUFFER | MANAGE BY |
|--|--|--|
| <ul style="list-style-type: none"> Tense, Tired, Frustrated, Overwhelmed -43% behavioral -45% cognitive Procrastination, Irritability -39% behavioral -37% cognitive | <ul style="list-style-type: none"> Worship Depressive Symptoms Weight Gain Insomnia Stress Pain | <ul style="list-style-type: none"> Talking to Family/Community Family Health Resources/Deaf Clergy Healthcare Professionals Using Mutual Support Activities Using Mental Exercises Getting Help Family, Friends, Volunteers Going to House of Worship Using Relaxation Techniques |

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