

**CHANGING THE TRAJECTORY OF ALZHEIMER'S:  
REDUCING RISK, DETECTING EARLY SYMPTOMS,  
AND IMPROVING DATA**

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

SECOND SESSION

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**TUESDAY, JUNE 19, 2018**

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

The Committee met, pursuant to notice, at 2:28 p.m., in room SD-106, Dirksen Senate Office Building, Hon. Susan M. Collins (Chairman of the Committee) presiding.

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

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

The CHAIRMAN. The Committee will come to order.

Good afternoon, everybody, and welcome to all the advocates and families from all across America. We are absolutely delighted to have you here.

I want to explain a little bit why I am the only one starting the hearing right now. As luck would have it, unfortunately, two roll call votes have just been scheduled, and one has just started. So in all of my time in the Senate in 21 years, I have never missed a roll call vote, and most of my colleagues are over voting right now. But I am going to start the hearing, give my opening statement. Then we will do a recess so that I can go vote, and then when we come back, Senator Casey, the Ranking Member, will give his statement. I apologize for this interrupted approach to the hearing, but you just never know when votes are going to be scheduled.

One hundred years ago, infectious diseases such as pneumonia and tuberculosis accounted for almost half of all deaths. Today, because of advancements in public health, we can treat and prevent what once were among the most deadly diseases in our country.

Public health saves lives and has proven over the past century to extend lives as well. Since 1900, public health has added nearly three decades to our life spans. The leading causes of death are now chronic diseases including cancer, respiratory diseases, and stroke. Alzheimer's disease is the sixth leading cause of death in our Nation.

While we all may be familiar with the role of public health in protecting against communicable diseases, advances in public health are beginning to change the story for chronic diseases as

well. For breast cancer, for example, early detection and screening save lives. The earlier the cancer is caught, the better the prognosis.

We are here today to explore how we can tap into public health to rewrite the future of Alzheimer's disease, just as we have done for so many other diseases of the past.

An estimated 5.7 million Americans are living with Alzheimer's, costing our Nation \$277 billion a year, including \$186 billion in costs to the Medicare and Medicaid programs. If we continue along this trajectory, Alzheimer's is projected to claim the minds of nearly 14 million seniors and surpass \$1 trillion in costs by the year 2050.

Last year, when this sea of purple last gathered, we explored the arc of Alzheimer's from preventing cognitive decline to improving care for those living with dementia. We learned that there are some modifiable risk factors that may be able to slow the progression of this devastating disease. We saw that there are models of care that can reduce co-morbidities, prevent hospitalizations, and improve life for those living with Alzheimer's—and for their caregivers. Essentially, we sowed the seeds of a public health approach.

Today, with the start of summer in sight, we are here for the harvest. The BOLD Alzheimer's Act, which I co-authored with Senator Cortez Masto, would create the public health infrastructure we need to combat Alzheimer's and preserve brain health. Our legislation would establish Centers of Excellence in Public Health Practice dedicated to promoting Alzheimer's disease management and caregiving interventions as well as educating the public on this disease and brain health in general.

The Centers for Disease Control and Prevention are already doing tremendous work to combat Alzheimer's within the Public Health Road Map of the Healthy Brain Initiative. The Centers of Excellence created by our bill would implement this CDC Road Map.

BOLD would spread the opportunity for communities across America to create the capacity to combat Alzheimer's. Our legislation would help public health departments take key steps including education, early diagnosis, risk reduction, care management, and caregiver support.

Early diagnosis can make a real difference. Earlier detection of symptoms would provide individuals and families with the opportunity to prepare by planning their finances and to find help in navigating the challenges of dementia.

Early diagnosis also saves money. A new study following everyone alive this year shows that diagnosing Alzheimer's sooner would yield an estimated total savings of \$7 trillion in medical and long-term care expenditures. Just as we screen for cancer, diabetes, and other chronic diseases, appropriate screening for Alzheimer's is the first step to improving treatment.

Finally, at the heart of public health are data. BOLD would direct the CDC to expand its data collection of cognitive decline, caregiving, and health disparities.

Today the BOLD Act has 35 cosponsors, but I know by the time the members of this audience are finished with all their Hill visits that we will be up to 50, the challenge I gave you last night.

[Applause.]

The CHAIRMAN. Or better yet, 60, the number that assures Senate passage.

[Applause.]

The CHAIRMAN. I am proud of the actions that the State of Maine is taking to promote early detection and improve data collection. The Maine Center for Disease Control and Prevention has distributed the State Plan for Alzheimer's, including its special insert with cognitive assessment tools to help primary care professionals make early diagnoses.

Maine CDC has also collected data through the Cognitive Decline and Caregiver modules in its Behavioral Risk Factor Surveillance System. In Bangor, Maine, where I live, the Public Health Department has distributed hundreds of "Know the 10 Signs" brochures. In Kennebunkport, the Public Health Office nurses are hosting talks on Alzheimer's to connect people with resources.

It is important that we all note that Alzheimer's is not a normal part of aging. It is a disease. It is a public health issue with a course that potentially we can change. We have taken steps to increase funding enormously, from \$414 million when I first started working on this issue in 1999 to nearly \$2 billion today, and that is making a difference.

There are other steps that we can take to help prevent the risk of cognitive decline and to improve the lives of those living with the disease and their caregivers. This public health approach is not only empowering; it is the key to saving lives.

Public health has proven its power with infectious diseases. With common public health measures, we are now able to control and prevent infectious diseases better than ever before.

In the time that we are here today, more than 100 Americans will be newly diagnosed with dementia. Each and every one has a story—a life rich with memories and a future left to finish. While some of those precious memories may vanish due to Alzheimer's, we are here to boldly hold out hope for a better future.

I really appreciate your coming to Washington. Many of you who have been here before will recognize this suit. Yes, I bought it I think 15 years ago, and I swore that I would not retire it until we had better treatments or a cure for Alzheimer's.

[Applause.]

The CHAIRMAN. So it is woefully out of style, and I am really sick of it. So let us get on with the job. Thank you.

[Applause.]

The CHAIRMAN. I am now delighted to turn to our Ranking Member, Senator Casey, for his opening statement, and I am going to go vote. Thank you.

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

Senator CASEY. Chairman Collins, thanks so much. How do I top that?

[Laughter.]

The CHAIRMAN. Well, you have a purple tie.

Senator CASEY. I am getting close. This tie was just dry-cleaned yesterday, but at lunch I got a spot on it, so I will put that on camera.

[Laughter.]

Senator CASEY. I want to thank Chairman Collins for her leadership on this issue and for making sure that we had this hearing today and for all of you for being here—everyone here, but especially of course our witnesses who are providing testimony to us today.

We want to thank, of course, the advocates as well who have traveled very great distances to be here. I know many from Pennsylvania, but virtually every state is represented across our country.

The experience of living with Alzheimer's or a related dementia or caring for someone with the disease is unfortunately all too common. It is a disease that affects all communities, and it does not matter where you are from or how much money you earn. It affects so many Americans.

In our state alone, the State of Pennsylvania, an estimated 280,000 people ages 65 and over are currently living with Alzheimer's. And as we will hear from Secretary Osborne from Pennsylvania, that number may not tell the entire story. There may be over 100,000 more people living with related conditions in our state and hundreds of thousands more loved ones, friends, and neighbors who are doing their best to care for them.

As our population ages, these numbers will only grow, which is why we must take action now.

Last year I was pleased to join Chairman Collins in support of increased funding for research into finding a cure for Alzheimer's disease. The federal funding was increased by an additional \$414 million, bringing our annual federal research investment to \$1.8 billion. That is a big step, but as evidenced by the number of people in this room, it is not enough. So I am continuing to press for additional research dollars, as I know folks in both parties are.

We also need to ensure our communities and our health systems are able to meet the needs of those living with Alzheimer's and their caregivers. We need to improve our ability to diagnose the disease early so that we can slow its progression. We need to also make sure individuals and families do not just get a diagnosis, but also get the support they need to deal with the disease.

And we need to make sure that no communities are left out of these efforts. That is why I am cosponsoring bipartisan legislation introduced by members of this Committee—Chairman Collins, of course, and Senator Cortez Masto—to tackle these challenges.

The BOLD Infrastructure for Alzheimer's Act will help state public health systems like Pennsylvania's make real progress in the fight against Alzheimer's. And it is an example of the type of bipartisan cooperation that we need now more than ever.

It is my hope that the voices of our witnesses here today—and the voices of those of you in this room today—will help us get this bill to the President's desk. And it is my hope that your advocacy will help us secure a \$2 billion annual investment in research so that we can soon hold a hearing focused on treatment and on a cure.



I want to thank Chairman Collins again and thank everyone here. And, again, I will say to our witnesses we look forward to the testimony today.

I know that Chairman Collins indicated there would be a recess after her opening, and I was able to give my opening. We are now, or will be shortly, on the second vote, and we will recess now and resume when the Chairman returns.

Thank you.

[Applause.]

[Recess.]

The CHAIRMAN. The hearing will resume.

I want to welcome the cosponsor and a leader in the fight against Alzheimer's, Senator Catherine Cortez Masto. Thank you so much for being with us.

[Applause.]

The CHAIRMAN. And, Senator Jones, we are delighted to have you here as well.

I am delighted to introduce our first witness today, Marcia Gay Harden. For those of you who follow popular culture well, she really needs no introduction. She is known for her roles in films such as "Mystic River" and "Pollock" for which she won the Academy Award. She currently stars in the CBS medical drama "Code Black." In her real life, Ms. Harden is also a mother, a caregiver, and a strong advocate for Alzheimer's disease awareness. Last month she published a personal memoir—I have a copy here—which is entitled "The Seasons of My Mother: A Memoir of Love, Family, and Flowers." In her book Ms. Harden writes about her mother Beverly's battle with Alzheimer's disease, detailing the struggles, the small victories, and how their relationship evolved over time. Today Ms. Harden honors her mother's legacy in the way that all of us here honor our loved ones with Alzheimer's disease: by keeping our memories of them alive and by fighting to find a cure for this devastating disease.

Next I am very pleased to introduce Dr. Lisa McGuire, who leads the Alzheimer's Disease and Healthy Aging Program at the Centers for Disease Control and Prevention. Dr. McGuire has served at the CDC since 2004 and published more than 75 articles and book chapters on aspects of chronic health conditions, cognition, disability, caregiving, aging. You name it, she has written on it.

I would now turn to my colleague, the Ranking Member, to introduce our witness from Pennsylvania.

Senator CASEY. Thank you, Madam Chair. I am pleased to introduce Teresa Osborne, who is the Secretary of the Pennsylvania Department of Aging. Secretary Osborne has dedicated her career to working with and advocating for older Pennsylvanians. In her current position she works to implement the Pennsylvania State Plan for Alzheimer's Disease and Related Disorders. Earlier this month her department announced the formation of Pennsylvania's Alzheimer's State Plan Task Force. I am proud that Pennsylvania is leading the charge with these initiatives and am looking forward to Secretary Osborne's testimony.

I would also like to add, Madam Chair, we welcome a large contingent from Pennsylvania, including Phyllis Gallagher from Frackville, Pennsylvania. Phyllis testified in front of this Com-

mittee last year and has been a tireless advocate for those living with Alzheimer's and their caregivers in our home state, and we are pleased she could join us again today.

Thank you.

The CHAIRMAN. Thank you. I heard that there was actually a special bus that came down from your state.

Senator CASEY. Yes.

The CHAIRMAN. So that is very impressive. But I want it known there are a lot of Mainers out there, too.

[Applause.]

The CHAIRMAN. Next I am delighted to introduce one of my constituents, Dr. Gareth Howell, an associate professor at the Jackson Laboratory in Bar Harbor, Maine. Dr. Howell co-leads the Alzheimer's Disease Precision Model Center at the Jackson Lab, and that was established by a \$25 million grant from the National Institute of Aging in partnership with—and I am looking at Senator Donnelly now—the Indiana University School of Medicine. And I know that this is a terrific project of which he is proud as well. Dr. Howell has authored more than 55 publications and received numerous prestigious awards for his work.

Senator Scott very much wanted to be here to introduce the final witness that we will hear from today, Ms. Cheryll Woods-Flowers, from Mount Pleasant, South Carolina. Ms. Woods-Flowers served as a caregiver and a court-appointed conservator for her father when he was diagnosed with Alzheimer's disease in 2004. She will tell us her father's story, her experiences in caring for him, and why she has remained such an active advocate and resource for others. Thank you for joining us as well.

Ms. Harden, we will start with you. Thank you.

**STATEMENT OF MARCIA GAY HARDEN, ACADEMY AWARD WINNING ACTRESS AND FAMILY CAREGIVER, LOS ANGELES, CALIFORNIA**

Ms. HARDEN. Thank you. I am honored to be here, and I am humbled to speak with so many as we come to Washington in hopes of tipping the scale.

Thank you, Chairman Collins, Ranking Member Casey, and members of the Committee for the opportunity to testify today on the impact Alzheimer's disease has on my family and families across the country.

As I look around me, I am grateful to see so many people gathered in this room today. But a scary statistic tells us that one or more of us, and certainly one or more of our children, will develop Alzheimer's disease. There is no known cure; the symptoms are devastating. And, to date, there are no survivors of Alzheimer's.

Alzheimer's is an insidious, cowardly disease that needs all of our voices, the voices of families, of our elected officials, and the voices of our Nation to galvanize and find a cure. It is my prayer that with your help, advocacy, and funding, this generation is able to celebrate the first survivor of Alzheimer's.

Congress has worked in a wonderfully bipartisan manner to quadruple Alzheimer's and dementia research funding at the National Institutes of Health since 2011 and continues to be deeply committed to providing the Alzheimer's and dementia researchers

with funding to move research forward. However, more needs to be done so we can discover the cause of Alzheimer's and find a cure.

Every 65 seconds someone in the United States develops Alzheimer's, and that number will nearly double by 2050. Almost two-thirds of Americans with Alzheimer's are women. These numbers frustrate, sadden, and, more importantly, anger me, and there is nothing more motivated than a pissed-off woman.

[Laughter.]

Ms. HARDEN. Alzheimer's disease first came into my life in 2011 when my strong, witty, vibrant mother was diagnosed. So let me tell you a little bit about my Mom, Beverly Harden.

She is one of the bravest women I have ever met. She raised five children while being stationed all over the world as my Dad served our country as an officer in the United States Navy. For months at a time, Mom would be alone with five children to feed, bathe, teach, and love. While we were stationed in Japan, she fell in love with ikebana, the art of Japanese flower arrangements, and it kept her grounded and connected to the beauty of life through nature. In fact, Mom went on to become the president of Ikebana International's most distinguished chapter right here in Washington, DC, but she does not remember that. She accompanied me to the Oscars in 2001. She does not remember that either. Her beautiful husband passed away in 2002, and she does not remember that either.

One of the first times I noticed my Mom having memory problems was around 2005 when we were traveling to Canada. We had boarded the plane, and she could not remember where she had just put her passport. So she checked her purse. Several minutes later, she forgot again and so checked once more. And, again, a third time. She became frantic, she was aware that something was wrong and that she should not keep forgetting where her passport was. But she did not want my help; she was in anguish. She wanted to string the moments together herself, with no gaps. Over time, those kinds of moments became more frequent, and in 2011 she was diagnosed with Alzheimer's disease.

As we all know too well, Alzheimer's disease causes memories to evaporate. One minute a person can recall a detail of their favorite novel, the function of a spoon, or the fact that tulips bloom in the spring, and the next minute it has disappeared. Eventually the names and finally the faces of loved ones are also memories that have evaporated, and soon the meaning of their lives evaporates. They are deprived of the validation of the memory of their lives. They do not remember who they were. They do not know who they are.

As a family, we focus on her care and on maintaining her dignity. We have sold my mother's home in anticipation of the mounting costs of caregiving. And it infuriates me how Alzheimer's becomes a stealthy thief, robbing families of their finances and security and forcing its victims to live only in the moment. For my mother, there is only the present with no connection to her past, without the rich tapestry of her life to tell her story. There is no dimension, just dementia. I see her concentrate, I see her try to speak the right words, I see her try to connect the memory to

words. And through it all, I see her eyes smile, but it seems to me that the smile is just a little bit wounded these days.

We do not know what the future holds, and we are scared. Will we eventually have to give up our own jobs to care for my mother? What will happen when the money runs out?

As I watch my Mom decline, I find myself worrying about my children or about me having Alzheimer's, and Alzheimer's has changed me. But my Mom always told me to repurpose my pain, to do something useful, so I have become an outspoken advocate. And the more I learn about the disease, the more motivated I am to make sure that people are educated about it.

I partnered with the Administration for Community Living for a nationwide campaign called "What is Brain Health?" which aimed to raise awareness about brain health while empowering older adults to make the most of their brains as they age, with a particular emphasis on early detection and diagnosis. Early diagnosis allows people to access available treatments, participate in support services, and if they choose to, very importantly, enroll in clinical trials.

As scientists continue to search for a way to prevent, cure, or slow the progression of Alzheimer's through medical research, public health can also play an important role in promoting brain health and cognitive function and reducing the risk of cognitive decline. It is imperative that we as a country invest in a nationwide Alzheimer's public health response to achieve a higher quality of life for those living with the disease and their caregivers.

One of the ways that we can make that investment is through legislation introduced by you, Chairman Collins, and your colleague Senator Cortez Masto, called the BOLD, or Building Our Largest Dementia, Infrastructure for Alzheimer's Act. It is endorsed by the Alzheimer's Association and the Alzheimer's Impact Movement, and BOLD would create an Alzheimer's public health infrastructure across the country to implement effective Alzheimer's interventions and focus on important public health issues like increasing early detection and diagnosis and reducing risk.

There is nothing good about Alzheimer's. It is not a disease where one can make lemonade from lemons. And yet through it all, my beautiful mother has managed to teach me, even through the destruction of her capabilities and creativity, that there is such a thing as an indestructible spirit. And it is because of this indestructible spirit that I know she would want to help others by raising awareness about this horrible disease.

The battle against Alzheimer's is a battle we must win. If we do not, it will cripple our Nation. As my father would say, we must pull ourselves up by the bootstraps. We must do our duty to the American people and fund and fight this battle, and we will win.

Thank you for your time.

[Applause.]

The CHAIRMAN. Thank you so much for your very moving testimony and your challenge to all of us.

Dr. McGuire.

**STATEMENT OF LISA C. MCGUIRE, PH.D., LEAD, ALZHEIMER'S DISEASE AND HEALTHY AGING PROGRAM, NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION, CENTERS FOR DISEASE CONTROL AND PREVENTION, DEPARTMENT OF HEALTH AND HUMAN SERVICES**

Dr. MCGUIRE. Chairman Collins, Ranking Member Casey, and members of the Committee, thank you for this opportunity to share CDC's efforts to address Alzheimer's disease and related dementia. My name is Dr. Lisa McGuire, and I lead the Alzheimer's Disease and Healthy Aging Program at the Centers for Disease Control and Prevention.

Alzheimer's is the only top-ten cause of death in America that cannot be prevented, cured, or even slowed. An estimated 5.7 million Americans of all ages are living with Alzheimer's in 2018. By 2050 we expect that number to rise to 14 million people.

Alzheimer's disease places a significant emotional and financial burden on people with the disease, their families and caregivers, and the health care system. Until we have a cure for Alzheimer's, CDC and its public health partners play a critical role in helping those 5.7 million people and their families. We work closely with state and local public health agencies by providing technical assistance, up-to-date scientific knowledge, cognitive decline and caregiving data, and promoting effective interventions to improve the health of Americans with cognitive decline and their caregivers.

Not only are more people living with Alzheimer's disease, but Alzheimer's disease-related deaths have increased by 55 percent from 1999 to 2014. Additionally, as people choose to age in place, one in four of those deaths of persons with Alzheimer's now occurs at home. As these numbers increase, caregivers become even more critical. We know that nearly one in four adults report providing care to a family member or friend in the past year. While some aspects of caregiving can be rewarding, caregivers for persons with Alzheimer's disease often report higher levels of anxiety, depression, and poorer health outcomes than their peers. The needs of caregivers is a public health issue that CDC remains focused.

First funded for Alzheimer's disease in 2005, CDC launched the Healthy Brain Initiative, providing leadership in a number of national efforts. In 2007 we developed our first road map, the National Public Health Road Map to Maintaining Cognitive Health. CDC and the Alzheimer's Association will release the third public road map later this year, in 2018, with an updated plan of 25 actions for state and local public health departments that are focused on accelerating the progress of risk reduction, early detection and diagnosis, safety and quality of care for people living with a cognitive impairment, and most importantly, caregivers' health.

Perhaps the greatest accomplishment of the Healthy Brain Initiative to date is the improved data collection. To measure the public health burden of cognitive decline and caregiving in the United States through the Behavioral Risk Factor Surveillance System, ongoing collection, analysis, and interpretation of data is pivotal to identifying and addressing gaps in program delivery, monitoring and evaluation of progress, and achieving health care goals.

States and jurisdictions use these data, often the only available source of state-level data, to develop Alzheimer's disease plans, in-

crease awareness, and guide elder justice and emergency preparedness efforts for the one in nine middle-aged and older adults who reported that their memory has worsened in the past year. CDC has state-specific fact sheets and maintains a free and easy-to-use Web site where researchers and the public can view and utilize the data for their state.

Public health has a critical role to play in combating the issue of Alzheimer's disease and related dementia. As the evidence grows about the risk factors and effective disease interventions, CDC, with the support of Congress and public health professionals across the country, will continue to draw on our expertise to continue to improve health, well-being, and independence of those with Alzheimer's disease and their caregivers through our Healthy Brain Initiative and the Road Map series.

Thank you for your focus on this critical public health issue, and I look forward to your questions.

The CHAIRMAN. Thank you very much, Doctor, and thank you for the work that the CDC is doing.

Now to learn more about the state perspective, I am pleased to call on Secretary Osborne.

**STATEMENT OF HONORABLE TERESA OSBORNE, SECRETARY,  
PENNSYLVANIA DEPARTMENT OF AGING, HARRISBURG,  
PENNSYLVANIA**

Ms. OSBORNE. Good afternoon. Thank you, Senator Collins and Senator Casey, for the opportunity to testify at this incredibly important hearing.

As I sit before you today, I am in complete awe of each and every one of the over 1,200 advocates, including the 50 Pennsylvanians hailing from Pennsylvania soil who gathered here today and have spent this past day courageously sharing their stories of love, devastation, and hope for a world without Alzheimer's. As Secretary of Aging for the Pennsylvania Department of Aging, I am humbled to join them as together we raise our voices for all of those impacted by Alzheimer's.

In my role I have the honor of serving at the pleasure of Governor Tom Wolf, who has made it a priority that we in Pennsylvania uphold the provisions of the Older Americans Act, an act that calls us to serve as visible and effective advocates for older Americans, including the 3 million Pennsylvanians who are age 60 years of age or older. And for us, in the year 2020, that year of perfect vision, one in four Pennsylvanians will be 60 years of age and older. And in Pennsylvania, we believe that the Alzheimer's trajectory can be influenced and changed.

Pennsylvania's current infrastructure, anchored by our State Plan on Aging, which is required under the Older Americans Act, and our State Plan on Alzheimer's and Related Disorders is in perfect alignment—perfect alignment—with the Committee's already recognized need to further invest in a nationwide Alzheimer's public health response that will promote better treatment and care for those living with Alzheimer's.

While my written testimony outlines in great detail the first two points just mentioned, I will focus the remainder of my verbal testimony on the need and the opportunity before us to better leverage

Older Americans Act services for the millions of Americans and the hundreds of thousands of Pennsylvanians with Alzheimer's or a related disorder.

All told, one in 12 Pennsylvania families are impacted by Alzheimer's or a related disorder. Moreover, nearly 675,000 Pennsylvania caregivers are providing billions of dollars in unpaid care to loved ones with dementia.

From our lens at the Pennsylvania Department of Aging, whenever we talk about health care and the elderly, we immediately pivot to three landmark federal programs, all of which were enacted in 1965: Medicare, Medicaid, and the Older Americans Act. And while Medicare and Medicaid began as basic health care programs, over the years they have evolved where they now provide Americans with improved access to quality and affordable health care coverage. But the Older Americans Act was created by your predecessors in Congress to bear the responsibility for community planning for aging programs and to serve as a catalyst for improving the organization, coordination, and delivery of aging services in every state.

For these past 53 years, in communities across the country, state units on aging, in partnership with their network of local Area Agencies on Aging, through the provision of those Older Americans Act services, help older Americans. They help older Americans remain healthy, stay connected with their communities, avoid hospitalizations or rehospitalizations, and defer altogether or transition from nursing homes. Older Americans Act services deliver vital programs that are low cost and high quality, including assistance in the home with personal care, accessing nutritional programs, or attending adult day service programs.

Moreover, the Older Americans Act-funded National Family Caregiver Support Program explicitly acknowledges the needs of families of older people in their caregiving role, including serving caregivers of individuals of any age with Alzheimer's disease.

Like many if not all of you on this prestigious Committee, every day I have the privilege to listen to concerned citizens who are either currently caregivers, who have been caregivers, who anticipate being a caregiver, or citizens who are receiving care or will need care, because every one of us in this room will in our lifetimes fit into one if not all of those buckets. And just before this hearing, I gathered with Pennsylvania advocates listening to their stories, stories that while individualized for individuals such as Jim and Phil and Michelle and Tom, but to the collective, their stories are compelling, and they are challenging. They challenge me and hopefully all of us to use our voices for good, to move beyond the status quo, to do more, to do it differently, to do it better. And we need to do it better. We need to destigmatize Alzheimer's and dementia. We need to better invest in the aging services network in order to meet the needs of individuals with Alzheimer's and their caregivers, affording them the opportunity to age in place in the setting of their choice with their friends and their families with the dignity and respect that they deserve. By doing so, we will boldly transform the Older Americans Act from being a small but important program to one that bends the cost curve on entitlement programs by providing community-anchored long-term services and supports

in a more cost-efficient, accountable, and person-centered care manner so that, regardless of ZIP Code, we create dementia-friendly communities that better respond to and meet the needs of the most vulnerable among us.

Thank you for the opportunity to present this testimony. I look forward to any questions you may have.

The CHAIRMAN. Thank you very much for your testimony.

[Applause.]

The CHAIRMAN. It is a great pleasure for me to call upon Dr. Howell.

**STATEMENT OF GARETH HOWELL, PH.D., ASSOCIATE PROFESSOR, THE JACKSON LABORATORY, BAR HARBOR, MAINE**

Dr. HOWELL. Thank you. Good afternoon, Chairman Collins, Ranking Member Casey, and members of the Committee. Thank you for the invitation to be here today and for your work in support of Alzheimer's disease and dementia research. My colleagues at Indiana University also thank Senator Donnelly for his continued support.

Aging research has been a key area of investigation at the Jackson Laboratory, or JAX, for many years, originally in the State of Maine and now also in California and Connecticut. However, we have recently established a vibrant Alzheimer's disease research program that includes more than 40 scientists led by myself and Drs. Gregory Carter, Catherine Kaczorowski, and Kristen O'Connell. We aim to identify genetic factors that drive both susceptibility and resilience to AD. We also aim to understand how modifiable risk factors, such as diet and physical activity, contribute to AD. We are working with the scientific community in the U.S. and worldwide to leverage these findings to identify and test novel therapeutic targets.

It is incredibly challenging to identify the earliest stages of complex diseases such as AD in human patients since they occur before any recognizable symptoms emerge. However, this is where animal models of human diseases come in. Mice share 95 percent of their genes with humans, and so we focus on building accurate representations of human disease in mice.

Sadly, clinical trials for Alzheimer's disease have not yet been successful. One reason is the lack of targeting early or pre-symptomatic stages. However, another is the lack of animal models that faithfully reproduce key hallmarks of human AD. Therefore, I am really excited to be a part of MODEL-AD, a collaboration between Indiana University, JAX, Sage Bionetworks, and University of California Irvine, that was established through the generous funding from the National Institute on Aging in the fall of 2016. And you will be glad to know that in the 1-hour drive back from Bangor airport, we renamed the IU-JAX Alzheimer's Disease Precision Model Center to MODEL-AD, which is much more catchy and easier to read out.

[Laughter.]

Dr. HOWELL. MODEL-AD aims to create at least 50 new mouse models for Alzheimer's disease and test at least 5 new compounds for their potential to prevent, slow, or cure Alzheimer's disease. We are 2 years into this 5-year project. We have created more than 15



new mouse models that are being assessed for their relevance to human late-onset Alzheimer's disease, and as I show in the figure, using the same AD relevant measurements to those used to determine whether an individual is developing AD. This is a key advance that we have had in the field in the last few years.

We have also established procedures by which new compounds can be tested in mice and are discovering new biomarkers so patients can begin treatment at earlier stages than previously possible.

Importantly, MODEL-AD is governed by the same open science policy at other NIA-funded centers such as the Accelerating Medicines Partnership in Alzheimer's disease have been adhering to since their inception. All data will be made publicly available through a web portal created and managed by Sage Bionetworks. Also, all mouse models are made widely available to the scientific community, something that Jackson Labs has been doing for many years. While we wait for that cure, data show that changing lifestyles such as diet and physical activity is also likely to reduce incidence of AD.

If we could have the next figure? At JAX we are using mice to understand the contribution of modifiable risk factors for AD. Studies in mice have the advantage that, unlike the human population, genetics and other environmental stresses can be controlled to specifically determine the role of diet and physical activity on AD risk. Work in my lab and others showed that regardless of the diet they consumed, mice that exercise from young to middle or old age remain cognitively normal. Therefore, encouraging lifestyle changes for all ages should remain a public health focus.

Finally, a sometimes forgotten aspect of the mouse is that, just like the human population, genetically distinct or diverse mice exist. If we could have the final slide? However, most mouse studies are performed on one mouse strain that turns out to be resilient to memory loss. We believe this is an important contributing factor to the failure of translation of animal model studies to the clinic. Encouragingly, we now have data to show that, just like the human population, amyloid deposition leads to memory loss in some but not all mouse strains. We are now using these genetically distinct mouse strains to determine the genetic factors that control amyloid-induced memory loss. These genes and pathways can be targeted as potential treatments for AD and related dementia. We are also, and importantly, determining how genetic and modifiable risk factors combine to alter risk for AD.

In summary, research at the Jackson Laboratory and collaborations such as MODEL-AD are creating, validating, and testing new mouse models to develop strategies to prevent, slow, or treat Alzheimer's disease.

I express my thanks to the Committee for this opportunity and for its continued support of Alzheimer's disease research.

The CHAIRMAN. Thank you very much, Dr. Howell.

[Applause.]

The CHAIRMAN. Ms. Woods-Flowers.

**STATEMENT OF CHERYLL WOODS-FLOWERS, FAMILY  
CAREGIVER, MOUNT PLEASANT, SOUTH CAROLINA**

Ms. WOODS-FLOWERS. Thank you so much for having me today. Chairman Collins, Ranking Member Casey, and members of the Committee, thank you for the opportunity to testify today about my experiences as a caregiver for my late Dad. I hope my story will bring more awareness to this awful disease that we all call “Alzheimer’s.”

My father, Richard Allen Novak, passed away in February—so it is kind of right here, so you all will have to forgive me for a minute—after living with Alzheimer’s for nearly 16 years. When he was 18, my Dad left his home in Wisconsin to join the U.S. Navy. That brought him to Charleston, South Carolina, where he would meet and fall in love with my Mom. That story gets told a lot of times. My Dad worked hard throughout his career in the Navy and the civil service, retiring in 1988, and then he started a successful woodworking business. He will be remembered for his love of dogs, people, his amazing Christmas light displays that always drew lines of cars, and his love for his family including 6 children, I am the oldest of the 6, 11 grandchildren, and 14 great-grandchildren.

Before my Dad was diagnosed with Alzheimer’s, it was not something that my family knew much about. Sixteen years is a long time. My Mom started noticing that my Dad seemed to be having trouble remembering where he left things. He was taking longer with errands. We knew that he must be getting lost or turned around in a city that he had lived in for over 50 years. And he kept forgetting things that he was supposed to be doing.

In 2003, my parents took a trip to Florida, which they had done many times before. Dad left the hotel at 8 o’clock a.m. to get a tire fixed. At about 4 o’clock p.m. that day, my Mom called us to let us know they could not find my Dad. My Dad had not shown back up. My Dad did not have a cell phone, and they could not find him.

When he was eventually found, he had been crying, had not eaten all day, did not have any money. It was truly an eye-opening experience for my entire family.

After that, we knew that something was indeed wrong and we had to get him help. We took him to a specialist at the Medical University of South Carolina where he was diagnosed with Alzheimer’s at age 70 very early in his disease, which was indeed a benefit for my Dad and for us. Every day we lost a little bit more of him, including the last 5 years where my Dad, who never met a stranger, did not recognize any of us, anybody he ever knew, or even my mother that he was married to for 50 years.

In a way we were lucky that my Dad was diagnosed so early with the disease. The early diagnosis gave us that time to talk through what we would do, as easy as it is for six children to agree on anything. We were able to make good decisions for him. We started some interventions. He started on Aricept and Namenda right away and was on that drug almost until the time of his death. So the medications helped him with the symptoms and gave him a better quality of life. We also learned ways to work around the best way for him to be cared for and for him to have the best quality of life that he could.

After he was diagnosed, my sister Theresa and I were named as conservator and guardian, and we became his primary family caregivers. We sold his house that he and my Mom had bought 55 years prior. Thankfully, they made the decision to buy a home in a city with a great deal of appreciation, and that was what took care of him in a facility that was almost \$6,000 per month.

About three years ago, we got to the point when we put him there, and we found a great facility that was nearby us, but it certainly did not come, again, without a significant amount of expense. If he had not had that home—my parents raised six children on very little money, and there was no savings to take care of him. My Mom had been gone since 2005.

I have always believed it is never enough to sit around and just wait on somebody else to do something, and I know that you all know those people, too. If not me, then who will do it? About four years ago, I became an advocate with the Alzheimer's Association and have been participating in the Walk to End Alzheimer's because I want to be part of the effort to eradicate this terrible monster of a disease. We must make the public and health care professionals aware of the early signs of Alzheimer's disease. There needs to be a greater nationwide public health effort and infrastructure in order to increase early detection and diagnosis. Legislation like the BOLD Infrastructure for Alzheimer's Act will help do that. This legislation would establish Centers of Excellence to increase education to the public, health care professionals, and public health officials on Alzheimer's, brain health, and health disparities, as well as collecting much-needed data on Alzheimer's and caregiving.

Investing in a nationwide Alzheimer's public health response will help create a higher quality of life for those that are living with this disease, their caregivers, and also reduce associated costs. The thing that I found the most stressful in some of the facilities that we looked at, and in talking with some of my friends also going through this, is we tend to think about treating symptoms, forgetting that these are people, and they need to enjoy the best quality of life they can while they are going through a disease that takes a very, very long time. It is a long walk in most cases.

The last few days I have joined with 1,200 of my closest friends, the 1,200 advocates from all across this country to make our voices heard in support of the BOLD Infrastructure for Alzheimer's Act. I promised my Dad that I would be his advocate and voice as long as I am able to. I hope that my children and grandchildren will not have to think about these issues because a cure should and would be found and hopefully in time for me to see that and for my children to see that.

As a caregiver and an advocate, I am respectfully asking Congress to continue to make Alzheimer's research a priority by increased funding for Alzheimer's research at NIH by an additional \$425 million and to help families gets diagnosed early by passing the BOLD Infrastructure for Alzheimer's Act.

This is my first Father's Day—sorry, guys—without my sweet Dad. Thank you for listening to all of us and for all that you have done. Please continue to fight for everybody that is going through this disease. I appreciate it.

The CHAIRMAN. Thank you so much.

[Applause.]

The CHAIRMAN. That was wonderful. Thank you.

Thank you so much for your moving testimony. I can so relate to what you are going through, having lost my own father to the disease on March 10th, and this was my first Father's Day, too, and it really is painful. And I am going to end up like you if I keep talking like that.

[Laughter.]

The CHAIRMAN. I am going to switch to questions and start with Ms. Harden.

Ms. Harden, we talk a lot about statistics when it comes to this disease and about the cost, but there is another cost that cannot be measured in dollar signs, and that is the impact on the family when they get the diagnosis that a loved one has Alzheimer's disease, and grief really starts at that point of diagnosis.

I applaud you for giving voice to how you have coped with the emotional consequences of that diagnosis. Are there any resources that you have found particularly helpful or any that you wish had existed when you first learned of your mother's diagnosis?

Ms. HARDEN. That is a piercing question, and you are so right, the diagnosis of Alzheimer's of a loved one, of a family member, of a parent who is supposed to be leading the way forces the siblings to lead the way, and siblings usually do not agree about much of anything, but especially what Mom or Dad would have wanted. And what I have found is that it is a family disease, and it very often tears the family apart. They say it either brings out the best in the family or the worst in the family, and I think it brings out both in the family.

At the time we only had the "36-hour" book. That is what her doctor talked to us about, the "36-hour" care book. We also had the Alzheimer's Association, and they were helpful to us, but they could not tell us how to mend the differences of the family, of what Mom would have wanted. I wish we had had BOLD. I wish we had had something very specific to say this is what you turn to, this is where you understand resources and financing and diet and all of the things that we are learning about today.

We became fractured, to be honest. My family became fractured, and it has been a journey to pull us back together so we can give my mother the best care. Finances—we have no recourse for finances. When the finances run out, that is our question: What do we do then? How do we handle it when the finances run out?

So I think every little bit of awareness tips the scale. I keep thinking about, you know, AIDS and how the more voices came together, the more plans came together, the more it tipped the scale until we found a cure. And that is what I feel like we are doing today.

I will just say I felt like I was on a sinking ship, and I feel like in this room, everyone in here has the same—we are all on the same journey. And yet the ship—there is that phrase "at crank." "At crank" means the ballast is not balanced. And I feel like we are here pleading and following you to balance the ship so that we can continue this journey safely.

The CHAIRMAN. Thank you.

Dr. Howell, you mentioned in your testimony an issue that really matters to me, and that is, when federal funding is being used, to me we want to share the data, the results as broadly as possible. Could you elaborate on what Jackson Lab does to spread the word about the research that you are conducting and the new mouse models that you are developing?

Dr. HOWELL. Yeah, I can. Much of the data that we have already used in order to generate the first mouse models have come from publicly available data, and this is something that was established by the NIH, particularly the NIA, when they first established the collaborations that preceded ours, which was to better understand the human condition. And so as I mentioned, the Accelerating Medicines Partnership for Alzheimer's Disease, all that data was publicly available, and that really helped us to get a jump start on how and which mouse models we were going to create. But in MODEL-AD, we are living by the same standard, so whenever we create new data, that data goes to the same place that the AMP-AD is submitting their data to, and so it is all under the same—it is all in the same place.

We also have other Web sites. We are using online and resources. We are promoting our data at conferences, and apparently we are tweeting and all sorts of things. And then, obviously, the Jackson Lab has been a mouse model distributor for many, many years, and so we have leveraged that skill set to make sure that all of our mice are available without restrictions, which has also been something that has hindered Alzheimer's disease research in the past, so that we can get these mouse models to whoever wants to use them, particularly maybe pharmaceutical companies who have struggled in the past to get the latest mouse models. And so we are working closely particularly with Eli Lilly, for instance, in Indiana to make sure that they want to use our new models, and if they want to use them, then other pharma who ultimately lead the clinical trial efforts will also benefit from them.

The CHAIRMAN. Thank you.

Senator Casey?

Senator CASEY. Thank you, Madam Chair.

I want to start with Secretary Osborne. As I indicated earlier and as we all know, with Alzheimer's disease it does not matter who you are or where you live or what your background is. It affects every community and in some way or another almost every family.

You know that in our state we have got a major part of our population as well as land mass that is considered rural. We have 48 of our 67 counties considered rural in Pennsylvania. So we have got to make sure that no matter where a person lives that they have access to the treatment they need and the support that they need.

What can we do, Secretary Osborne, to make sure that individuals diagnosed with Alzheimer's disease who happen to live in rural areas, say one of those 48 counties in our state, that they have access to both services and supports?

Ms. OSBORNE. Thank you, Senator, for that question. It is one that we ask ourselves and our aging network and our partners on this journey, such as the Alzheimer's Association, every day. Researchers obviously will tell us that individuals living in rural

areas that are diagnosed with Alzheimer's disease or another related dementia already face unique challenges. Their challenge is just including a lack of transportation or limited access to health care without having to travel a great distance. Those challenges, they create even more stress on caregivers.

So for us, in order to help our rural communities, these public-private partnerships—and it is not just an aging issue. It has been pointed out to me time and time again, even with the Pennsylvania advocates I met with earlier today, this is a community issue. How are we best going to leverage our resources at the Department of Aging, with the Department of Health, with the Department of Human Services, and then parlay that down to the local level, that we are indeed working with local human service agencies in every rural community, plus the hospital system. And I can go on and on with regard to the need to constantly pivot back to better leveraging the resources entrusted to our care so that we can support caregivers, so we have health care communities that are established.

One of the easiest things that I feel that we can do is to work with our partners on creating these dementia-friendly communities, you know, where any of us live, work, worship, play, pray, the banks that we go to, the pharmacies, the groceries. Each one of us had a stake in this in terms of ensuring that individuals with dementia are understood, that they are valued, and that they are still able to contribute to their community, and by working together with our partners, we can ensure that our communities are dementia-friendly and that we can look out for one another and we can ensure that the most important story in all of this to be told is the individual living with dementia.

It was mentioned by many of my esteemed panelists here today, early diagnosis and early connecting to resources and services. If we can better detect, diagnose, and then better connect individuals with those low-cost, quality services at the home and community-based level, we will bend that cost curve so that we are not relying upon Medicare and Medicaid and higher costs of care such as nursing home facility level of care, as Cheryll described.

From our particular lens, as but one state in this effort, how we connect to the national plan so that communities all across this country, regardless of ZIP Code, that we have dementia-friendly communities that have resources available to help one another through this really devastating disease.

Senator CASEY. Well, I know you have been to a lot of those communities, if not every one, in our state that have both substantial health care needs as well as at least the potential for an access problem because of where they are. And you mentioned at the outset of your answer about the—you said the stress on caregivers. I wanted to focus on that for a moment, when it comes to caregivers, the remarkable, heroic work that they do. And we have got to make sure we are doing all we can to support them.

Many of the programs that you oversee for the Older Americans Act can help caregivers. Can you tell the Committee what the caregivers you speak to, what supports do they need and what services are most valuable to them?

Ms. OSBORNE. Thanks, Senator, for this question. No different than you, when you journey home to Lackawanna County on the weekends, and I do the same, inevitably somebody asks you a question with regard to "I need help with X, Y, and Z." It happens to all of us, I am certain.

To me, just this past weekend, I had two friends who approached me with exactly what you just described: "I need help with affording care. I do not know where to turn. I need respite care. My siblings will not help me."

So for us in Pennsylvania, how are we going to best ensure that for the individuals journeying with this disease and for the caregivers who help support them, that again we can detect and connect them with local resources. By and large, the Older Americans Act services, they do support senior community centers that are safe harbors for individuals with early onset dementia in particular, to continue to go to, receive access to nutritional services, receive access to support, and a safe harboring community. But we also have an opportunity under Older Americans Act services, under the National Family Caregiver Support Program to ensure that we are connecting their caregivers with services. And, by and large, the most requested service that I get asked about by caregivers is access to respite. They need a break themselves. Whether it is for a couple of hours, a couple of days to go to a family reunion, to go to a class reunion, just to go to dinner, just to take a shower, how do we connect them with that respite service? And how can we truly break open the National Family Caregiver Support program so that we do not have any barriers to ensuring that whatever that caregiver is identifying, that we can help them provide that service without a list of barriers, to be able to assist them with that.

So we are excited about the work that has been done to enable the aging network in the Commonwealth of Pennsylvania to be certain, but also across this country because of work this Committee has advocated for with the Family Caregiver Program. But we also know we have a lot more work to do. And as Cheryll mentioned, public safety programs, you know, if we had a federal stamp on a public safety program that can actually ensure that first responders have the tools and technology that they need in order to aid them in safely reuniting a missing individual with their family, you know, just like an Amber alert, we all know what that means. But it is not the same with individuals with Alzheimer's and dementia who, regretfully, get lost from their family members for lots of reasons, as Cheryll just described. So those public safety programs are critical to be part of the infrastructure of how we can boldly move forward to ensure that we are meeting the needs of caregivers today as well as the ones in the future.

Senator CASEY. Thank you very much.

The CHAIRMAN. Thank you.

Senator FISCHER?

Senator FISCHER. Thank you, Chairman Collins and Ranking Member Casey, for holding this important hearing and for your leadership on this issue and on the BOLD Infrastructure for Alzheimer's Act. Thank you both.

I would also like to thank the witnesses for being with us today and for sharing your personal experiences. The news when a family member or friend is diagnosed with Alzheimer's rocks everyone in its wake, and as all of you know, that official news is one of the many steps in a very long journey. Again, I would like to thank you all for sharing your stories.

This is a question for the entire panel, and we can go down the row if that would be helpful. What is it about the BOLD Act that you find the most promising or central as we continue to spread awareness and where really we can work toward more of an understanding about this very evil disease? Ms. Harden, would you like to start, please?

Ms. HARDEN. Certainly. I do not know the specifics of the act to speak to exactly which is better, you know, which part of it is better than the other. But what I know about it is that it talks early detection, and one of the things that really affected my family was that we lost a huge window with my mother. We did not have early detection, and so we lost my mother's voice in determining what she wanted for the rest of her life, how she wanted to live and, frankly, how she wanted to die. And we did not get to have that question, and so the kids had to answer that question for her. That is something I never want my children to have to answer for me. So I have been an advocate for early detection.

The other thing that I really love when I heard about it, what I am learning about it, is that it unites the Nation, and I think that is such a wonderful future to look to, that it unites the Nation as we care for ourselves as we age, that we have a plan. I am a "I want a plan" girl. I feel much safer with a plan. And so that is what it feels to me—I had a metaphor last night that Senator Collins is literally in a darkened tunnel with a torch saying, "Here is the way out, and I am not getting out until everybody is out," so kind of lighting the path for us, and I think that is what we need. I think we need direction.

Senator FISCHER. Thank you. Doctor?

Dr. MCGUIRE. Thank you for that question. I cannot comment on the specifics of the BOLD Act, but I can say that our states across the U.S. are poised to act and to help us with this public health crisis. And the BOLD Act will allow for some national awareness and some convening that could help states really dig in and make a difference.

Senator FISCHER. Thank you. Secretary?

Ms. OSBORNE. I appreciate the question very much, and I am probably one of the most hopeful people in the room, but I was also taught by my Dad to realize that hope is not a plan.

So when I heard of the BOLD Act and the folks in the Alzheimer's Association and others who work with us on our state plan on Alzheimer's disease talk to me about the BOLD Act, and then we dived into it a little bit more on our end, Pennsylvania is already well positioned, as I have in my written testimony and briefly spoke about with regard to my verbal testimony. We are incredibly well positioned because of our current infrastructure. We have a state plan on aging under the Older Americans Act. We have a state plan on Alzheimer's and other related disorders, and that is great. We have plans. Now, how are we going to put those



plans into action? And it is because of the partners, many of whom are gathered with me here today from Pennsylvania, from the Alzheimer's Association, they are Alzheimer's advocates, they are ambassadors, in order to ensure that together all of us will work toward that plan of BOLD, in particular.

Our infrastructure also includes two NIA-funded Alzheimer's research centers—one at the University of Pennsylvania in Philadelphia, at the Penn Memory Center, and the other at the University of Pittsburgh. For us in Pennsylvania, we are incredibly excited about the opportunity to actually host an Alzheimer's Care Center of Excellence. We feel that we are leading the way under the Governor's administration with regard to all kinds of public health issues, and I mentioned a little bit earlier, when it comes to our opportunity to communicate, coordinate, and collaborate our efforts across our health and human services agencies—and the Department of Aging is just but one part of that—the Department of Health, the Department of Human Services, the Department of Drug and Alcohol Programs, the Department of Insurance, Department of Transportation—I can go on and on and on.

But we need to work better together, break out of our silos, which is probably the most overused words ever, with regard to how we are going to use the resources.

Senator FISCHER. But also the most important.

Dr. MCGUIRE. I agree. How are we going to use the resources entrusted to our care, whether they are resources that come, you know, thankfully and gratefully, from the Federal Government, whether they are taxpayer dollars, whether—in the Commonwealth of Pennsylvania, 75 percent of our budget at the Pennsylvania Department of Aging comes from the Pennsylvania lottery. So hopefully everybody here will buy a Pennsylvania lottery ticket.

[Laughter.]

Ms. OSBORNE. It benefits older Pennsylvanians. Got to play to win. But that does support the work that we do, which is why I so passionately advocate for the BOLD Act and why I really wanted to pivot my testimony toward the Older Americans Act, which is often not the third pillar of the stool of those three main federal entitlement programs, such as Medicare and Medicaid, but we have an opportunity to bend that cost curve by providing better services, low-cost, high-quality services, in the homes and communities of our older Americans. We can do so much better, and this BOLD Infrastructure will allow us to do that.

Senator FISCHER. Thank you. Doctor?

Dr. HOWELL. I think whenever I hear things like early diagnosis, I guess what excites me as a researcher is that the earlier we go, the better, the more likely therapeutics will work. And so as a researcher, this act would allow us to get at earlier and earlier stages of Alzheimer's disease that we can then both understand through basic research in, for instance, animal models, but also then using them as a discovery tool to then turn the question on its head and to ask whether what we have identified in our animal models of disease actually reflects what goes on in the human population, because it is certain that the earlier we start the treatment, the more successful that treatment will be. And I think as an advocate, with my friends from the Maine chapter of the Alzheimer's Association,

I get a lot more of an understanding about advocacy and care, and that seems to be exactly what is needed.

Senator FISCHER. Thank you.

Ms. WOODS-FLOWERS. The BOLD Infrastructure Act, it comes home to me in a number of ways. In the late 1980's, my first husband was diagnosed with cancer, and the biggest thing for me was having a road map. What in the world am I going to do? Where am I going next? What is the plan? What is the infrastructure? And with cancer, that is laid out for you. Right away, you know, you are diagnosed. We are going to do this and this and this and this. And it gives the family members and the person who is fighting the disease an understanding of what is going on, but they have more sense of control in exactly where their life is going. And with control, it decreases the amount of stress for a caregiver and certainly for somebody who has some sort of disease.

One of the things that I learned that has really just taken the breath out of me at times as I have been involved with Alzheimer's is the number of people who do not come under what we would normally call "older," the people in their 40's and 50's. I mean, I am just over 60—now the whole world knows. This is on C-SPAN.

[Laughter.]

Ms. WOODS-FLOWERS. And I do not consider myself older. But we are seeing people in their 40's and 50's and 60's that still should be productive members of this society that do not come under any act for older people and they are given this diagnosis, it will absolutely—we were thrown for a loop, but we expect—my Dad was getting older, but if that was somebody in their 40's or 50's or 60's, just imagine what that does to your life when you still have children at home, when you still have huge responsibilities for caregiving for your family, but also probably as productive members of society.

Fifty percent of the people that are living with this disease have yet to be diagnosed. This has got to be a public health issue. People that do not have access to facilities like the Medical University of South Carolina—I am blessed to live where I live because we had lots of resources, people that were willing to see my Dad on a short-term basis. People that are in the rural areas do not have that kind of access, so this has got to be a public issue, a public health issue. We have got to establish Centers of Excellence, so this is going—so we look at brain health. As I have been told by physicians, the brain is probably one of the least understood parts of the human body. That has got to change, because it is absolutely impacting the ability of people to enjoy their lives the way that they should.

Senator FISCHER. Thank you. As most of you here, my family has faced this terrible disease. I thank you for what you do.

The CHAIRMAN. Thank you very much, Senator, and thank you for cosponsorship of the BOLD Act.

Senator Cortez Masto?

Senator CORTEZ MASTO. Thank you, Chairwoman and Ranking Member, for this hearing. Thank you all. I think we are done. You have pretty much said everything that we need to get started on.

But let me say this, because I think you touched on this, Ms. Woods-Flowers, and that is this: The idea that this act that we are

talking about, the BOLD Act, really sets the tone that this is a public health crisis, and we are creating an infrastructure that is necessary for that coordinated care plan that we have all been talking about today. It is a coordinated plan that we can tap into an infrastructure to address everything. And I say that because I just came back from Nevada—and I know there are Nevada folks here as well—and we had a roundtable discussion in northern Nevada, and I had a lot of my stakeholders at the table to talk about where are the gaps. Where do we need to work together? Because I will tell you, in Nevada we have a State Aging Division. They are phenomenal. You do an incredible job. An incredible job. And I so agree with you that now is time to coordinate and connect everybody together because of what we just heard.

And, Ms. Gay Harden, I am going to touch on this. One of the gaps we have is the doctors—not that they do not want to be there, but they are not trained to think about this when you first come in and there is an early diagnosis or detection to connect you with the services that you need in your community. That is the No. 1 thing that I heard from the folks in Nevada that I was sitting with. How do we bring them in? And then you brought in the first responders. It is the same thing. So by creating this idea that this is a public health crisis, we have an infrastructure that now we can all tap into and start education, start early diagnosis, start the detection, and then start the help and assistance that is necessary for everybody to tap into it. That is the key. That is what we are trying to achieve here. So I so appreciate the questions and the comments that you had today.

Let me touch on one area, which is the data collection, which for me is key. I am a data geek, and I think that is where everything starts, collecting the data and we learn from the data and it takes us in directions that are so important.

But one of the things I am particularly concerned about when it comes to dementia-related health disparities is those that occur in our communities of color, American Indian and Alaska Native communities, LGBTQ communities, and people with intellectual and developmental disabilities.

So, Dr. McGuire, let me ask you this: Can you tell me what kind of health disparities the CDC's data collection has already discovered?

Dr. MCGUIRE. Thank you very much for that question. Through our Behavioral Risk Factor Surveillance System, we are asking people to evaluate their own memory performance. We call it "subjective cognitive decline." And we also ask caregivers about their specific caregiving situation. So we know one in nine Americans report that their memory has worsened in the past year, and we know about one in four Americans is caring for a loved one or family member.

So to answer your question, we do know disparity-wise, we do know that we see higher numbers of individuals that are African American that are reporting the subjective cognitive decline, also individuals that are Hispanic/Latino, and also American Indian and Alaska Natives. Through our work, we are working with some tribal organizations to increase awareness in tribal communities and to really try to think about risk reduction. So we have some

messages and campaigns that are being developed about managing your blood pressure in middle age because we know that managing your blood pressure in middle age can help reduce your risk of having dementia later on. And we are developing those messages for tribal communities, for the providers, and for the general population as well.

Senator CORTEZ MASTO. Thank you. Is there anything that we have not talked about today—I am going to open it up to the panel—where you see gaps or other challenges that we should be focused on?

Ms. HARDEN. I think there are gaps in teaching our young people about Alzheimer's and how their diet and lack of exercise might be a precursor. I talk to my kids about it, and I guarantee you, I get, "Oh, Mom." You know, "We have got to clean out the pantry." But they are interested in it, and they are changing their own diets. And I think I heard you say, Doctor, that mice, no matter what they ate, did you say, that if they were exercising, they were not showing signs of dementia. And so I thought that was just a really fascinating bit of information. Apparently you have to sweat if you exercise, which is not so hot, in my opinion, but I will do it if that is what needs to be done. So I think education for the youth and the young ones, really middle school, elementary school, because they are eating lots of sugar.

Senator CORTEZ MASTO. Thank you. Anyone else?

Dr. HOWELL. I will just expand on that. So the challenge with exercise and diet is that, you know, under controlled conditions, a strain of mouse does not get the same degree of aging in the brain as those that do not exercise. The challenge is in the human population. We know very little about how our genetics might interact and change the way in which exercise might be important. When I talk about my exercise research, I often get somebody who stands up and says, "Well, my father was a marathon runner and then developed Alzheimer's at the age of 60." And so, sadly, it is not simply exercise and everybody will be fine.

So, what we can do is using both human studies and animal studies to really understand how the genetics interact with the environmental factors, such as exercise, such as diet, in order to reduce risk. What I think is really important, though, is for sure, as a population and society, it is going to help. We cannot predict who it is going to help, but overall it is going to help. It should reduce numbers, or it should reduce the incidence of Alzheimer's disease. So the more we can do to encourage our children, you know, and older to get out there and do some exercise and balance their lifestyle is going to be important.

Senator CORTEZ MASTO. Thank you. Thank you all. I appreciate you being here.

The CHAIRMAN. Thank you very much, Senator, for your leadership.

Senator Warren?

Senator WARREN. Thank you, Madam Chair, and thank you for your leadership on the issue of Alzheimer's disease. This is one of the toughest public health challenges facing America today, and I am very glad to be a cosponsor of the BOLD Infrastructure for Alzheimer's Act which you and Senator Cortez Masto introduced to at-

tack the problem of Alzheimer's using a public health framework. I am glad to be sitting between you, also in purple, and that we are here today for this. You know, I think this bill is a critical step in the fight against Alzheimer's and Congress should pass it.

There are a lot of things we need to do to tackle this disease: increase funding for Alzheimer's research, yes; raise awareness; improve screening; provide better access to palliative care; strengthen our support for caregivers. It is a long, long list out there. And today I just want to talk about one piece to all of this, and that is making sure that seniors with Alzheimer's get safe, quality care wherever they are living.

Dr. McGuire, let me start with you. Why is it important that Alzheimer's patients, especially those in the early stages of the disease, receive high-quality care?

Dr. MCGUIRE. Well, it is important for those in early stages of the disease to receive high-quality care because we know diagnosing Alzheimer's disease and related dementia can help the patients and their family better manage the health care. We know that 95 percent of people who do have Alzheimer's and related dementia also have another chronic health condition. So it is important that when the person does have Alzheimer's and dementia that we continue to maintain and manage that chronic condition so we can prevent preventable hospitalizations, which can be costly and also very stressful to the person who has Alzheimer's, as well as their family and caregivers.

Senator WARREN. Thank you. You know, when a loved one gets an Alzheimer's diagnosis, families do everything they can to try to get quality care, and many families turn to assisted living facilities to help provide this care. Around 40 percent of the 830,000 Americans living in assisted living facilities have Alzheimer's, and the numbers are only going to increase as our population ages.

Back in 2015, Senators Collins, Hatch, McCaskill, and I asked the Government Accountability Office to look at how states and the Federal Government oversee the care provided to Medicaid patients at assisted living facilities, and this year they got back to us with bad news. According to the GAO, over half the states do not adequately track the number of serious health and safety problems in assisted living facilities. More than a dozen states do not make this health and safety information available to the public.

So if I could, let me ask you, Ms. Woods-Flowers, I understand you recently lost your father to Alzheimer's. I am very sorry for your loss.

Ms. WOODS-FLOWERS. Thank you so much.

Senator WARREN. Thank you. You spoke about how you worked with your sister to manage your father's care and how you chose to place him in an assisted living facility. In considering assisted living facility options for your father, was it important to you that the services he received were high quality and safe?

Ms. WOODS-FLOWERS. It absolutely was. We visited probably six different facilities, and we were looking for things, like we wanted to make sure that the facility was clean, that it was well staffed—at that time we did not understand what “well staffing” is, and I might just say a little bit more about that—and that it included activities, social, otherwise, so that his quality of life would be as

good as it could be. We knew that he was not going to learn anything new, but we also knew that we wanted his brain challenged some part of the day, that we did not want him sitting in a chair all day waiting between meals, just waiting from one meal to the next.

What we found was, the facility we found, we were very blessed by because it was clean and he was—he did have some activities until the last year when he was really unable to participate in those things.

The biggest challenge that we saw was that the staff is not trained to deal with Alzheimer's patients. They would be fine in assisted living. They would be fine in a skilled nursing facility. They do not understand and we cannot find any law that says they have to be trained in any way to deal with an Alzheimer's patient. And they have different needs than somebody in assisted living and in skilled nursing. My father would not eat unless he was reminded to eat. He would not pick up any piece of—if it was a sandwich, he was not picking it up. So we made his menus every single day—every single week so that he could get things that he could pick up with a fork or a spoon, because he was not going to pick up that sandwich, he was not going to pick up a piece of pizza or anything. And those are very distinct things for Alzheimer's patients, and these are people taking care of them in those facilities, and they do not have that training.

Senator WARREN. I very much appreciate the point that you are making, and I appreciate your sharing your experiences here. Families are doing their part, and I believe that Congress needs to step up, too, and ensure that we collect data on where these health and safety violations occur, make sure that you have enough information up front to make a decision about the facility you want to choose for your father, and know what kind of care and what kind of training the people have there.

I am working on legislation to fix this problem. I hope that we will be able to work together on it in this Committee. I think this is important. I understand. The fight against Alzheimer's is a fight for patients, it is a fight for caregivers, it is a fight for families, it is a fight for communities. And it is an honor to be here with all of you in this fight.

Ms. WOODS-FLOWERS. Thank you so much, Senator.

Senator WARREN. Thank you.

The CHAIRMAN. Thank you, Senator.

The very patient Senator Jones.

Senator JONES. You have to be patient when you are number 99 in seniority.

[Laughter.]

Senator JONES. Thank you, Madam Chairman and Ranking Member Casey, for doing this, and thank you to all the panelists. And for all of the sea of purple out there that I am seeing, thank you for all that you are doing. Ms. Woods-Flowers, thank you especially because I always appreciate a South Carolinian who can come in and give testimony without an accent, which is really nice.

[Laughter.]

Senator JONES. This is important to so many of us. It all hits us on a very personal level. My best friend's Dad, who was my second

Dad, died a number of years ago. I watched him go down, and then a few years ago, it hit my Dad. And he was a Navy man as well and is in assisted living now. Dad was the strongest man I have ever known, short in stature but like a rock in both his physical stature as well as his integrity and character. And it is, you know, a very sad Father's Day—he is still alive but to see him in the state he is in, because it affected not just his cognitive abilities but he's also been affected neurologically to where I walked him into the hospital a couple years ago, and he has never walked again. And it is very, very difficult.

And it is especially difficult on my Mom. I do not say she is a caregiver in the sense that she is working and constantly doing things. She is in the assisted living facility next door. But she visits him about every day, and just to see the man she has lived with for almost 69 years after a 2-week Navy courtship, I mean, literally first date on Wednesday, engagement on Sunday, and 2 weeks later marriage, and 69 years later she visits him every day. The emotional toll for her is extraordinary. I deal with it every day when I try to call back home and talk to her.

So this is really important to all of us, and it is why, Madam Chairman, I am happy—the BOLD Act was introduced before I got here, but I am happy to add my name as a cosponsor.

The CHAIRMAN. Thank you so much.

[Applause.]

Senator JONES. My question is a little bit more practical and probably a little bit more personal, given my age, and I am a first generation with someone who has this disease. We talk about early detection, but where is the tipping point where someone should recognize maybe I need to see someone about my memory. We all lose our keys, we do things. As we age, we are going to have memory issues. How do we recognize, how do we talk to people, whether it is through legislation or just the education process, about early detection? And where is the tipping point to literally go see a doctor and say, "Maybe I need to look at this"? And I think, Dr. Howell, maybe Secretary Osborne, maybe you two are the best, but, you know, Dr. McGuire, maybe you can chime in, too, just anybody.

Dr. HOWELL. Yeah, I mean, that is a tough question. Actually through education that we have been doing with the Alzheimer's Association in Maine, there are ten ways of recognizing it. There is no single way to say, OK, here is the tipping point. Losing your keys but finding them again is not too much of a worry. That should be fine. Repetitive behavior is one thing that people talk about, forgetting that they have said something or done something very recently. And I think for early diagnosis it is really important to diagnose prior to any signs of memory loss. By the time there is significant memory loss that is recognizable in an individual, there may well be a lot of pathology in the brain that has not been detected. And so when we think about early diagnosis in our animal studies, we think more about, you know, way before cognitive decline or cognitive changes, and we think of things like blood, changes in the blood, potentially a blood test for high risk for Alzheimer's. This is something that we are really all working hard on.

A retinal exam, an eye exam is another thing that could be possible. The retina is a piece of the brain sticking out of the skull,

very easy to access, very cost effective to assess. We are really only beginning to explore the potential for early diagnosis by something other than cognitive changes, which I think are very important and for all of the reasons that have been suggested in terms of saving money. But in terms of treatments, you even maybe want to consider treatments prior to cognitive decline.

Senator JONES. Secretary Osborne, do you want to add anything to that?

Ms. OSBORNE. Sure, I appreciate that. You know, in part of the comments that I rendered, I talked about the destigmatization of Alzheimer's disease. Like many in the room, I had a family member recently that we were intervening, actually. We realized that things were getting a little bit out of control for him and his wife. Married for 64 years, and he said to me that he was embarrassed to tell anybody the signs that his wife was having, you know, very humble. They had a little card shop that they ran in the Scranton area, and they knew a lot of folks in the community. He did not want people to know what he was dealing with on a daily basis. So even for him to talk to us about, you know, how do I not be embarrassed that I am seeing these signs, but who do I go to? He did not even have a diagnosis. His physician never shared with him, "Your wife has Alzheimer's disease," just said, "oh, you know, it is memory loss. It is this, it is this. Do not worry about it."

So how do we get to that early detection, that detection at all, connecting them with services and that they are not afraid of talking about it?

One friend told me over this past weekend, knowing that I was coming here to Washington today, they run an assisted living facility, so for the Senator before you and the comments made about assisted living, I appreciate them very much, because in those facilities every day we have caregivers helping caregivers who are dealing with the challenges that families are facing, where they are exhausted, they are frustrated, they are guilt-ridden. They are worried about how they are going to pay for that level of care. What happens after their money runs out? And they all point back to the minute that they are rendered that diagnosis and hear it for the first time, the response is usually a pretty palpable silence, that there is such a stigma attached to, "Oh, my God, this happened just now to me and my family."

So the more we can talk to folks within our communities about how to not be embarrassed, about how to look for those signs—I love the program that was mentioned earlier with the Administration for Community Living. You know, how do we ensure that we are doing that in all 50 states and every community within those 50 states. That is what is so exciting about the BOLD Act, to get that infrastructure in place that we are better coordinating, communicating, and collaborating to make sure that these services, these supports, these programs are in the hands of the Americans who need them.

Senator JONES. All right. Well, thank you.

Dr. McGuire, do you want to say something real quick?

Dr. MCGUIRE. Yes, please. So from our Centers for Disease Control and Prevention data, we know that approximately half of people who are experiencing changes in their memory that is worse in



the past year are actually talking to their health care providers. So my colleagues on the panel here have mentioned stigma and awareness. So we do need to reduce the stigma. We need to make people know it is OK to talk with their health care provider, and just because you are experiencing memory loss or declines in your memory does not mean you have Alzheimer's disease. You need to see a health care provider to get your symptoms checked out, to rule out any possible treatable conditions that may be causing the symptomatology, and the Medicare annual wellness visit does cover cognitive screening and assessment. And so there are mechanisms out there for Americans to get their cognitive screening done, and we just have a lot of work to do together to move this forward.

Ms. HARDEN. I have a thought. I do not have to show any signs of breast cancer to get a mammogram, so maybe there is no tipping point. Maybe it becomes something so common that we test for it before.

Senator JONES. Excellent. Thank you to the panelists.

Thank you, Madam Chairman, for calling this hearing. I appreciate it very much.

The CHAIRMAN. Thank you very much, Senator. Before you have to leave, I want to give an update on the number of cosponsors because due to the efforts of this group and your joining us, we now have a total of 40 cosponsors, including me.

[Applause.]

The CHAIRMAN. And just today, in addition to picking up Senator Jones, we picked up Senator Donnelly, Senator Gillibrand, and Senator Bennet, just so those of you who are from those states know that it counted.

[Applause.]

The CHAIRMAN. I want to thank all of our witnesses here today for your testimony. You have really made a difference in coming forward and helping us to better understand the personal and the economic toll of this devastating disease, the hope that we all can have as we embrace a new approach, the public health approach, the research that is going on, the collaboration that Secretary Osborne referred to so often. And it gives me hope that as we continue to work on this, we are going to see effective treatments, means of a prevention, and someday a cure. And it will be because of the work, the passion, the energy of all of you who are such extraordinary advocates.

I know that each of you here has been touched in some way by this disease, and sharing your views, your experiences, whether as a caregiver or as someone who has been affected more directly—actually, caregivers are very directly affected, as I know. There are no two stories that are alike, but each case of Alzheimer's disease causes a ripple effect through the entire family and through our communities, and that is why we need a new public health approach. That approach is a bold one, and it is one that I believe will help us move forward.

Last night at your wonderful dinner, which was so inspiring, one of the advocates put it best when she said, "Let us make Alzheimer's disease a memory." And I thought that was such a wonderful way to put it. So I am stealing that line from now on.

[Laughter.]

The CHAIRMAN. And when I speak about Alzheimer's disease and the work that I am doing, that is how I will end my speeches.

I do want to take a moment today to thank my staff, which has worked so hard, and Senator Casey's staff as well, and to acknowledge and thank Dr. Melissa Batchelor-Murphy. Melissa has served for the past 6 months as a health and aging policy fellow on our Aging Committee staff. She came to us from the Duke School of Nursing and brought with her expertise in geriatrics and specifically dementia care. So this marks Melissa's last hearing with us, and now she is going to go back into academia. But she told me that we can still call her often. So, Melissa, thank you very much for all of your work, and we value all of your contributions.

[Applause.]

The CHAIRMAN. Senator Jones, do you have any final words?

Senator JONES. Just a moment, Chairman Collins, and let me again thank you for the incredible work and dedication not just for these hearings but for the work you do. And I really appreciate that, and your staff and Senator Casey's staff.

And to all of you here, not just our witnesses but to everyone here, not just for the work you do, but for raising the awareness because that is just so important. It is great to research. It is great to deal with people every day. But raising the awareness is so important for folks to try to deal with this disease and make it a memory. And you are having an effect. I can tell you on a personal level. On Father's Day this year, my family gave me a new gym bag and athletic shoes and everything to encourage me to do those kinds of things that I need to be doing in my life.

As the population ages, the number of people living with this disease and the number of loved ones, friends, and neighbors are only going to grow unless we do something. We have to do everything we can to advance research into treatment for paracommunities and health systems to meet the challenge of the future. And I am looking forward to being on this bill, to continue to work with colleagues in the Senate on a really—this is a bipartisan effort. This has no political stripes whatsoever to keep up the fight. And I encourage everyone here to keep up the fight as well.

So thank you, Madam Chairman. Thank you.

The CHAIRMAN. Thank you very much, Senator.

[Applause.]

The CHAIRMAN. Let me end this hearing by thanking the Alzheimer's Association and AIM for all of your work and for encouraging all of these advocates to come to Washington. My thanks to each and every one of you.

Committee members will have until Friday, June 29th, to submit questions for the record, so there may be a few more questions coming your way.

This concludes our hearing. Thank you so much for being here.

[Applause.]

[Whereupon, at 4:33 p.m., the Committee was adjourned.]

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## **APPENDIX**

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## **Prepared Witness Statements**

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**Prepared Statement of Marcia Gay Harden, Academy Award-Winning  
Actress and Family Caregiver, Los Angeles, California**

Thank you Chairman Collins, Ranking Member Casey, and members of the Committee for this opportunity to testify today on the impact of Alzheimer's disease on my family and families across the country.

As I look around me this morning, I'm grateful to see so many people gathered in this room. But a scary statistic tells us that one or more of us, and certainly one or more of our children, will develop Alzheimer's disease. There is no known cure, and the symptoms are devastating; every memory of life is wiped away, including forgetting how to breathe and how to swallow. To date, there are no survivors of Alzheimer's. Unlike cancer and AIDS, many individuals living with Alzheimer's, like my mother, can't speak for themselves, because they reach a point in the disease where they are no longer able to speak out about it. Alzheimer's is an insidious, cowardly disease that needs all of our voices, the voices of families, of our elected officials, and the voices of our nation to galvanize and find a cure. It is my prayer that with your help, advocacy, and funding, this generation is able to celebrate the first survivor of Alzheimer's disease. Congress has worked in a wonderfully bipartisan manner to nearly quadruple Alzheimer's and dementia research funding at the National Institutes of Health (NIH) since 2011, and continues to be deeply committed to providing the Alzheimer's and dementia community with funding to move research forward. However, more needs to be done so we can discover the cause of Alzheimer's and find a cure.

Every 65 seconds someone in the United States develops Alzheimer's disease, and that number will nearly double by 2050. According to the Alzheimer's Association, an estimated 5.7 million Americans are living with Alzheimer's in 2018. Almost two-thirds of Americans with Alzheimer's are women. In truth, it frustrates and saddens me to hear these numbers. More importantly, it angers me—and I have found anger to be a great motivator. Amazing what a person can accomplish when they get pissed off enough.

Alzheimer's disease first came into my life in 2011 when my strong, witty, vibrant mother was diagnosed. As a daughter and a caregiver, I hope my story will bring awareness to this horrible disease.

Let me tell you a little bit about my mom, Beverly Harden. She is one of the bravest women I have ever met. She raised five children while being stationed all over the world as my dad pursued his career, serving our country as an officer in the United States Navy. For months at a time, mom would be alone with five children to feed, bathe, teach and love. While we were living in Japan, she discovered ikebana—the ancient art of Japanese flower arrangement. She found that ikebana could transform her home into a place of spiritual reflection and beauty. Ikebana's most important rule of forming an asymmetrical triangle with the flowers—representing shin, soe, and hikae—or heaven, earth and man—kept her grounded and connected to the beauty of life through nature. Mom went on to become the President of Ikebana International's most distinguished chapter, Chapter 1, right here in Washington, DC, but she doesn't remember any of that. She accompanied me to the Oscars in 2001. She doesn't remember that. Her beloved husband passed away in 2002. She doesn't remember that either.

One of the first times I noticed my mom having memory problems was around 2005 when we were traveling to Canada. We had boarded the plane and she couldn't remember where she had just put her passport—so she checked her purse. Several minutes later, she forgot again, and so checked once more. And again, a third time. She became frantic, she was aware that something was wrong and that she shouldn't keep forgetting where her passport was. She didn't want my help; she was in anguish, wanting to string the moments together herself, with no gaps. Over time, those kinds of moments became more frequent and in 2011 she was diagnosed with Alzheimer's disease.

As we all know too well, Alzheimer's disease causes memories to evaporate. One minute a person can recall a detail of their favorite novel, the function of a spoon, or the fact that tulips bloom in spring, and the next minute it has disappeared. Eventually the names, and finally faces of loved ones, are also memories that have evaporated, and soon, the meaning of their lives evaporates—so it is for my mother.

Today 50 million people worldwide suffer this evaporation. Rich, fertile minds, Ph.D.'s and scientists, plumbers and dancers, presidents and senators, doctors, inventors, teachers and firemen, the disease doesn't discriminate. These people are now deprived of the validation of the memory of their lives. They don't remember who they were. They don't know who they are, they forget how to talk, how to walk, how to arrange flowers. Watching my mom forget herself and her many contributions to life—it pisses me off. So my siblings and I do what my father taught us

to do—we “pull ourselves up by the bootstraps”—never mind that we wear high heels. We know what he meant!

As a family, we focus on her care, and on maintaining her dignity. We’ve sold my mother’s home in anticipation of the mounting costs of caregiving. It was one of the hardest decisions that we’ve had to make so far; the loss of her home is something that we all felt, with such a dread and sense of helplessness that it has somewhat devastated us. I keep reminding myself we are doing the best we can, with the tools and knowledge that we have. We want things to be as they were before but the disease continues to march forward. Our funds are limited, these are uncharted waters, and we’ve had to adjust, to prepare for the unknown, to calculate all possibilities and most importantly ensure her comfort, care, and safety. My mom now lives in a smaller house, located on a lake with birds and familiar neighbors close by. It is near medical resources and a church, as well as my sisters who shower her with love and visits, and caregivers who take wonderful, dutiful and exacting care of her as she ages with Alzheimer’s. But we don’t know what the future holds, and we are scared. Will we eventually have to give up our own jobs to care for my mother? What will happen when the money runs out?

Did you know eighty-three percent of help provided to older adults in the United States comes from family members, friends or other unpaid caregivers? And nearly half of those caregivers provide care to people with Alzheimer’s. Last year, caregivers of people with Alzheimer’s or other dementia provided an estimated 18.4 billion hours of unpaid assistance—valued at \$232.1 billion—unpaid care.

It infuriates me that this is how Alzheimer’s becomes a stealthy thief, robbing families of their finances and security, and forcing its victims to live only in the moment. For my mother there is only the present, with no connection to her past, without the rich tapestry for her life to tell her story. No dimension, just dementia. I see her concentrate, I see her try to speak the right words, I see her try to connect the memory to words and through it all, I see her eyes smile, but it seems to me, the smile is a little bit wounded these days.

There is no medicine yet, no surgery yet to grasp the dangling thread of memory, to rethread the needle and weave it back into her tapestry and connect thoughts to memory and life experience, to allow her to remember her life. Instead, as the patient and family wait impatiently, more threads unravel, more dangling thoughts, the tapestry of her life slowly disintegrates, the picture is blurred and memory is lost.

This disease has no dignity, and yet, my mother has somehow managed to keep hers. And even as the pitch-black darkness of this hideous disease advances, the core of my mom—her elegance and humor and love of family and God—has remained the same. I think of it as her light that cannot be extinguished.

As I watch my mom decline, I find myself worrying about me or my children having Alzheimer’s. My mom always told me to repurpose my pain, to do something useful, so I read a lot about the disease and ways to reduce my risk—things like exercising, a healthier diet, and sleeping better.

Alzheimer’s has changed me. I’ve become an outspoken advocate. I’ve done campaigns to raise awareness of the early signs of dementia and Alzheimer’s. The more I learn about the disease, the more motivated I am to make sure that people are educated about it.

It is so important for people and doctors to be aware of the early signs of Alzheimer’s disease and other dementia. In 2015, I partnered with the Administration for Community Living at the Department of Health and Human Services for a nationwide campaign called “What is Brain Health?” that aimed to raise awareness about brain health while empowering older adults to make the most of their brains as they age—with a particular emphasis on early detection and diagnosis. I learned that approximately 50 percent of individuals with Alzheimer’s and other dementia have not been diagnosed and of those who are diagnosed with Alzheimer’s only about 33 percent are aware of their diagnosis. My participation in the “What is Brain Health?” campaign only solidified my belief in the value of raising awareness about Alzheimer’s and brain health, because when people are diagnosed earlier, they can have hard but empowering conversations with family that will allow them to take some control over their destiny. They can take steps to create a care plan with their families and their physician. They can control what time they have left before the darkness takes over. Early diagnosis also allows people to access available treatments, participate in support services, and if they choose to, enroll in clinical trials.

Last month, I worked with Maria Shriver and the Women’s Alzheimer’s Movement during their national initiative Move for Minds—and was especially hopeful at the work they are doing. I learned from them that women are at a greater risk for this disease. According to the Alzheimer’s Association, 2 out of 3 brains that de-

velop Alzheimer's belong to women. Why? I've always known our brains are different and I was inspired by the call to action to research the why of it all—the how of it all. What role hormones, sleep, having babies and menopause may play in Alzheimer's disease? We must fund more research on women's brains.

As scientists continue to search for a way to prevent, cure or slow the progression of Alzheimer's through medical research, public health can also play an important role in promoting brain health and cognitive function, and reducing the risk of cognitive decline. It is imperative that we as a country invest in a nationwide Alzheimer's public health response to achieve a higher quality of life for those living with the disease and their caregivers.

One of the ways we can make that investment is through legislation introduced by Chairman Collins and Senator Cortez Masto, called the BOLD or Building Our Largest Dementia Infrastructure for Alzheimer's Act. Endorsed by the Alzheimer's Association, the BOLD Infrastructure for Alzheimer's Act would create an Alzheimer's public health infrastructure across the country to implement effective Alzheimer's interventions and focus on important public health issues, such as: increasing early detection and diagnosis, reducing risk, and preventing avoidable hospitalizations.

Every little act we do, does make a difference. Caregivers always feel guilty they can't do enough, but I want caregivers to know that we have to be gentle with ourselves. Being in the moment with the person, knowing they have an ability to recognize the familiar even if they can't verbalize it, is comforting. Once my mother said to me: "I don't know who you are, but I know you are important to me. When you came into the room, your face made me feel happy." I've learned to say to my mom, "It's OK if you don't remember me, I will always remember you."

There is nothing good about Alzheimer's—it is not a disease where one can make lemonade from lemons. When I think of my mom, I think of the beauty of her Ikebana, her delicate creations with lines for shin, soe and hikae, and how she was before. I don't want Alzheimer's to be her legacy. And yet, through it all, my beautiful mother has managed to teach me, even through the destruction of her capabilities and creativity, that there is such a thing as an indestructible spirit. It is because of that indestructible spirit that I know she would want to help others by raising awareness about this horrible disease. Through a daughter's eye, I share her story in hopes of keeping her legacy alive.

The battle against Alzheimer's is a battle we must win. If we don't, it will cripple our Nation. I want to close with some words from my Navy Captain father who was fond of quoting General Patton. Their spirits were similar despite their different military branches. This was one of his favorite Patton quotes: "All men are afraid in battle. The coward is the one who lets his fear overcome his sense of duty. Duty is the essence of manhood."

We must pull ourselves up by the bootstraps. We must do our duty to the American people and fund and fight this battle, and we will win.

Thank you for your time.





**Written Testimony**  
**Senate Special Committee on Aging**

**A Public Health Approach to Alzheimer's Disease**

*Prepared Statement of*

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Chairman Collins, Ranking Member Casey and members of the committee, thank you for the opportunity to share information on the public health approach to Alzheimer's disease and related dementias. My name is Lisa McGuire and I lead the Alzheimer's Disease and Healthy Aging Program at the Centers for Disease Control and Prevention (CDC), within the Department of Health and Human Services (HHS).

Alzheimer's disease places a significant emotional and financial burden on people with the disease, their families and caregivers, and the health care system. Unlike other leading causes of death, there is currently no known cure or definitive prevention for Alzheimer's disease. The growing burden of this disease has increased the visibility of Alzheimer's disease and related dementias at national, state, and local levels. Through the Healthy Brain Initiative, the CDC continues efforts to advance cognitive health in the public health arena.

#### **Background**

Dementia is a form of cognitive decline that seriously affects a person's ability to carry out daily activities. The most common form of dementia among older adults is Alzheimer's disease, which initially affects the parts of the brain that control thought, memory, and language. Alzheimer's is a devastating, progressive, and ultimately fatal disease that begins with mild memory loss and can lead to the loss of the ability to carry on a conversation and respond to the environment. People with Alzheimer's gradually lose the ability to care for themselves and to remain independent.

As people age, their risk of cognitive decline, including Alzheimer's disease and other dementias, increases. The growing number of older adults in the U.S. population has already placed unprecedented demands on aging services and the public health and health care systems. By 2030, 1 in 5 Americans, or 72.7 million, will be aged 65 years or older, and by 2050 the number of adults aged 65 years or older in the United States is projected to reach 83.7 million.<sup>1</sup>

An estimated 5.7 million Americans of all ages are living with Alzheimer's dementia in 2018.<sup>2</sup> This number includes an estimated 5.5 million people aged 65 and older and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's.<sup>2</sup> By 2050, the total number is projected to rise to 14 million people.<sup>3</sup>

### **Risk Reduction**

We do not yet fully understand what causes Alzheimer's disease. Age is an important risk factor. Researchers are actively investigating the role of genetics and increased risk of developing Alzheimer's disease. Researchers are finding evidence that some of the risk factors for heart disease and stroke, such as high blood pressure and high cholesterol, may increase the risk of Alzheimer's disease. There is also growing evidence that physical, mental, and social activities may reduce the risk of developing the disease. A 2015 Institute of Medicine (now known as the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine) report provides evidence-based recommendations to promote brain health for individuals, families, communities, health care providers and systems, financial organizations, community groups, and public health agencies.<sup>4</sup> HHS developed an online Brain Health Resource that offers current, evidence-based information and resources to facilitate conversations with older people and their families about brain health.<sup>5</sup>

In 2017, a National Academies of Sciences, Engineering, and Medicine expert committee evaluated a National Institute of Aging-funded report by the Agency for Healthcare Research and Quality's Evidence-based Practice Centers Program. It concluded that with respect to prevention of Alzheimer's disease and cognitive decline, cognitive training, blood pressure management for those with hypertension, and increased physical activity are supported by "encouraging although inconclusive evidence," and recommended pursuing additional research in these and related areas.<sup>6</sup>

### **Burden**

Not only are more people living with Alzheimer's disease, but Alzheimer's disease-related death rates are also increasing. Alzheimer's disease is the sixth leading cause of death in the United States, accounting for 4.1 percent of all deaths in 2014. It is the fifth leading cause of death among adults aged 65 years or older.<sup>7</sup> As there has been more success in reducing rates of deaths due to heart disease and cancer, more adults are living longer and, as a result, their risk for developing Alzheimer's disease increases as they age. Alzheimer's is the only top ten cause of death in America that currently cannot be prevented, cured, or even slowed.

Alzheimer's disease-related deaths have increased over the past 16 years in every race, sex, and ethnicity category, and will most likely continue to increase as the population continues to age.<sup>8</sup> Alzheimer's deaths significantly increased in 41 states and the District of Columbia from 1999 to 2014. Overall, the age-adjusted Alzheimer's death rate per 100,000 population increased from 16.5 (or 44,536 deaths) in 1999 to 25.4 (or 93,541 deaths) in 2014, an increase of 55%. In addition, studies have suggested that the Alzheimer's deaths reported on death certificates might be underestimates of the actual number of Alzheimer's deaths in the United States.<sup>9</sup>

### **Caregiving**

Family members and friends provide most of the care for people with Alzheimer's disease and related dementias who live in the community. While some aspects of caregiving may be rewarding, the health of those caring for persons with Alzheimer's disease or related dementias is often negatively impacted. These unpaid, informal caregivers — who are mostly family members or friends — often report higher levels of anxiety and depression and have poorer health outcomes than their peers who do not provide such care.<sup>10</sup> Caregivers themselves may have chronic health conditions, and providing care to others may interfere with their own self-care, as they give their attention to others and delay their own needs.<sup>11</sup>

The percentage of people with Alzheimer's disease who died at home increased from 13.9 percent in 1999 to 24.9 percent in 2014.<sup>7</sup> As the number of older Americans, Alzheimer's deaths, and persons with Alzheimer's dying at home all increase, so will the number of caregivers needed to provide care.

Older adults with Alzheimer's and related dementias are more likely than other older adults to have multiple chronic conditions. Among Medicare fee-for-service beneficiaries with Alzheimer's disease and other dementias, 95 percent had at least one other chronic medical condition.<sup>12</sup> Alzheimer's complicates the management of these other conditions, resulting in increased hospitalizations and costs.<sup>2</sup> For example, Alzheimer's and related dementias can negatively affect one's ability to:

- Manage medication
- Remember doctor's appointments

- Recognize and articulate the onset of new physical or emotional symptoms
- Seek assistance/care in the face of changes.

Because of the progressive nature of decline with Alzheimer's disease, the need for care also changes over time.<sup>13</sup>

These unique complications in turn contribute to caregiver burden, spiraling health care costs, and economic hardship for people and their families. In 2017, caregivers of people with Alzheimer's or other dementias provided an estimated 18.4 billion hours of unpaid assistance, which has an estimated economic value of \$232.1 billion.<sup>2</sup>

#### **Health Care Costs**

Alzheimer's and related dementia care also place a tremendous burden on the national health care system. Alzheimer's disease is the most expensive disease in America, as total payments in 2018 for all people with Alzheimer's or other dementias are estimated at \$277 billion, with Medicare and Medicaid expected to cover \$186 billion of those payments.<sup>2</sup> Total annual payments for health care, long-term care, and hospice care for people with Alzheimer's or other dementias are projected to increase to more than \$1.1 trillion in 2050.<sup>2</sup> Currently, one in five Medicare dollars is spent on the care of people with Alzheimer's. In 2050, it is projected to be one in every three dollars.<sup>2</sup>

#### **CDC Healthy Brain Initiative**

With congressional appropriations that began in 2005, CDC established the Alzheimer's disease-specific segment of our Healthy Aging Program and launched our Healthy Brain Initiative. Through this initiative and with continued congressional appropriations, CDC has been involved with and provided leadership in a number of national efforts. The Healthy Brain Initiative addresses cognitive health from a public health perspective to ensure that CDC informs state and local health departments about the importance of cognitive health.

In 2007, CDC partnered with the Alzheimer's Association to create the first in a series of road maps to integrate cognitive health and functioning into the routine practice of public health: *The National Public Health Road Map to Maintaining Cognitive Health*. The first Road Map proposed a set of 44 recommendations or actions. This landmark document served as both a call-to-action

and a guide for a coordinated approach to moving cognitive health into the national public health arena. The development of the Road Map was guided by a Steering Committee with representatives from a variety of organizations and agencies, including CDC, the Alzheimer's Association, National Institute on Aging, Administration on Aging, AARP, and other experts from across the nation.

Congress passed the National Alzheimer's Project Act (NAPA) in 2011 in recognition of the escalating public health, social, and economic consequences associated with Alzheimer's disease. NAPA created an important opportunity for federal agencies to review and coordinate their efforts related to Alzheimer's disease and related dementias. Since its passage, CDC has served as an active member of the Advisory Council on Alzheimer's Research, Care, and Services, which reports to the U.S. Secretary of Health and Human Services. *The National Plan to Address Alzheimer's Disease* (National Plan) was issued in 2012 by HHS, as mandated by NAPA. The National Plan is updated annually and seeks to expand our understanding of the causes of, treatments for, and prevention of Alzheimer's disease and related dementias, as well as increase support for people with Alzheimer's disease and related dementias and their caregivers.

Building on the National Plan, CDC and partners released a second road map entitled *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018* (Road Map) in 2013. The second Road Map lays out 35 actions the public health community can do to support brain health and caregivers. Over 200 organizations at the national, state, and local levels contributed to the development of this Road Map.

CDC currently funds the Alzheimer's Association and The Balm in Gilead, to accomplish the Healthy Brain Initiative Road Map's 35 action items. The Alzheimer's Association tracks cognitive decline and caregiving (using data from CDC's Behavioral Risk Factor Surveillance System optional modules), helps state public health agencies develop and revise Alzheimer's plans, and educates constituent groups about aspects of cognitive health and caregiving. The Balm in Gilead, an organization that primarily works with African American faith-based organizations, trains health professionals who are affiliated with African American health care organizations, such as the National Black Nurses Association and the National Medical Association, to recognize

the signs and symptoms of Alzheimer's and raises awareness of the disease through activities in faith-based communities.

A third Road Map, planned for release later in 2018, will outline how state and local public health agencies and their partners can continue to promote cognitive health, address cognitive impairment for people living in the community, and help meet the needs of caregivers. In developing this Road Map, a Leadership Committee consisting of members across many sectors met over a six-month period to examine progress to-date and identify leading public health issues for the next five years. The Leadership Committee identified actions from the previous Road Map that had not been fully accomplished and issues that would require continued effort in the coming years.

Twenty-five specific actions will be proposed in four traditional domains of public health: 1) educate and empower, 2) develop policies and mobilize partnerships, 3) assure a competent workforce, and 4) monitor and evaluate. The action items speak to critical issues of disease risk identification and risk reduction, diagnosis, education and training, caregivers, and evidence on impact of the disease.

The Road Map series promotes partnerships and ensures critical linkages at the national, state, and community levels, which is essential to the success of the National Plan. As of April 2018, 48 states and territories have published Alzheimer's disease plans and a few cities and counties have created regional plans. While these states have plans and are poised to take action, many lack resources and expertise to implement their plans and action items stemming from the Road Map series. There are a number of states that are tackling this looming public health crisis, however, and may serve as examples for other states.

#### **State Examples**

Recent work from the Utah Department of Health and the Colorado Department of Public Health and the Environment illustrate the lasting contributions that can be made when states have access to expertise and are able to implement their action items and state plans.

Two action items in the second Road Map are improving health care providers' ability to recognize early signs of dementia, including Alzheimer's disease, and educating healthcare providers about validated cognitive assessment tools.<sup>14</sup> Utah contracted with HealthInsight to improve early detection of cognitive impairment in Utah. HealthInsight interviewed providers about their experiences and processes in conducting cognitive assessments during the Medicare Annual Wellness Visit. The resulting report, *Cognitive Assessments during Medicare Annual Wellness Visits*, was sent to all Utah primary care physicians, along with a list of resources for people with cognitive impairment. It also included a recommendation from the Utah Department of Health's executive director for routine cognitive assessment during the Medicare Annual Wellness Visit using both a primary and follow-up assessment tool.

The Colorado Department of Public Health and the Environment partnered with the Alzheimer's Association Colorado Chapter to deliver its *Approaching Alzheimer's: First Responder Training* program. Emergency Medical Service providers receive many calls to assist people with Alzheimer's and other dementias, yet often lack the preparation for the unique physical, behavioral, and communication challenges related to dementia. Colorado marketed the availability of the free, in-person training through its internal networks and all 11 of Colorado's Regional Emergency and Trauma Advisory Councils. The training helps first responders serve people with Alzheimer's in emergencies.

CDC has an established public health network and the ability to work with states to implement disease prevention and health promotion programs, including state plans and Road Map action items. Examples such as these from Utah and Colorado demonstrate the many ways that CDC, states, and national organizations work together to achieve more than working alone.

#### **CDC's Data Collection**

CDC has a unique surveillance capacity to monitor the health status of older Americans and those living with Alzheimer's disease and other dementias.

CDC utilizes its state-based Behavioral Risk Factor Surveillance System (BRFSS), the only system of its kind in the United States, to gather baseline information on self-reported subjective cognitive



decline (a precursor to Alzheimer's disease), as well as caregiving. CDC works with partners and states to gather information on the prevalence of subjective cognitive decline and caregiving among adults, through BRFSS surveys. BRFSS remains the only source of public health data at the state, territorial, and local levels for most states in these topic areas.

The Subjective Cognitive Decline Module assesses and monitors self-reported cognitive decline. The Caregiver Module collects information about the health, quality of life, and behaviors of caregivers, including caregivers of persons with dementia, to better understand their activities and needs. Both of these modules are optional for states to implement with CDC support. CDC was able to provide support to 33 states, the District of Columbia, and Puerto Rico to add BRFSS questions about subjective cognitive decline to their surveys in 2015; and 16 additional states to add the questions in 2016. CDC was able to provide support to 24 states to add questions about caregiving in 2015; and 14 additional states, the District of Columbia, and Puerto Rico to add caregiving questions in 2016. States and jurisdictions use this information to develop state plans, increase awareness about the needs of these populations, and guide elder justice and emergency preparedness efforts for older adults.

Those looking for more general data on the health status of older adults in the United States can find this information using CDC's Healthy Aging Data Portal, which provides free access to a range of national, regional, and state data on older adults. Users can examine data on key indicators of health and well-being of older Americans, such as tobacco and alcohol use, screenings and vaccinations, and mental and cognitive health. Portal users may retrieve CDC data by indicator or geographic area, and then download datasets, develop reports, and create customizable maps, charts, and graphics for all participating states, regions, or by individual state in which data were collected. The Portal provides a snapshot of the health of older adults in their states in order to prioritize and evaluate public health interventions.

CDC also supported expansion of the National Health and Nutrition Examination Survey (NHANES) to include cognitive data. NHANES is a nationally representative sample of about 5,000 persons that over-samples persons aged 60 and older, African Americans, and Hispanics. For the first time, in the 2011-12 and 2013-14 NHANES cycles, cognition was included in both

the interview questions (2 questions about perception of memory status) and in the mobile exam center (3 validated and standardized performance measures of cognitive functioning). Results from these survey questions are expected soon.

As part of the Healthy Brain Initiative, in 2010, CDC also was invited to lead a workgroup to develop national objectives related to dementias, including Alzheimer's disease. CDC co-chaired this effort with the National Institute on Aging and worked with the large set of stakeholders. As a result, there are two objectives related to Alzheimer's disease and other dementias in Healthy People 2020. The first objective shows the proportion of older adults aged 65 and older with a diagnosis of dementia, who are aware of their diagnosis. The second objective tracks preventable hospitalizations for persons with diagnosed dementias over the age of 65. The Healthy Brain Initiative worked with researchers to develop baseline measures and monitor these measures over the 10-year span to track progress over time.

### **Conclusion**

Spurred by Congressional recognition of Alzheimer's as a public health issue and the growing need to help patients and their families, Alzheimer's disease and related dementias are now prominent parts of our nation's health care discussions. However, much work remains. While there is no cure at this time, much can be done to improve the health and wellbeing of those with Alzheimer's disease and related dementias. Many people with Alzheimer's and their caregivers are unaware of tools, resources, supports, and services available to them. Better dissemination of this vital information for people with Alzheimer's and their caregivers will improve disease management. The Healthy Brain Initiative and Road Map series will continue to provide states and communities with information about Alzheimer's and other dementias in order to support their residents. Further action in the areas of epidemiology, data collection, and wide-scale promotion of evidence-based interventions can significantly enhance our understanding of the Alzheimer's disease crisis as well as have a tremendous impact on the lives of those people living with Alzheimer's disease and their caregivers.

- <sup>1</sup> U.S. Census Bureau. An aging nation: the older population in the United States, population estimates and projections. Washington, DC; 2014 May. [www.census.gov/prod/2014pubs/p25-1140.pdf](http://www.census.gov/prod/2014pubs/p25-1140.pdf)
- <sup>2</sup> Alzheimer's Association. 2018 Alzheimer's disease facts and figures. *Alzheimers Dement* 2018;14(3):367-429. Access at [https://www.alz.org/documents\\_custom/2018-facts-and-figures.pdf](https://www.alz.org/documents_custom/2018-facts-and-figures.pdf)
- <sup>3</sup> Hebert LE, Weuve J, Scherr PA, Evans DL. Alzheimer disease in the United States (2010–2050) estimated using the 2010 census. *Neurology*. 2013;80:1778-83.
- <sup>4</sup> Institute of Medicine. Cognitive Aging: Progress in Understanding and Opportunities for Action. Washington, DC: National Academies Press; 2015.)
- <sup>5</sup> <https://www.nia.nih.gov/health/brain-health-resource>
- <sup>6</sup> National Academies of Sciences, Engineering, and Medicine. Preventing Cognitive Decline and Dementia: A Way Forward. Washington, DC: National Academies Press; 2017
- <sup>7</sup> Heron M. Deaths: Leading causes for 2015. *National Vital Statistics Reports*; vol 66 no 5. Hyattsville, MD: National Center for Health Statistics. 2017.
- <sup>8</sup> (Taylor CA, Greenlund SF, McGuire LC, Lu H, Croft JB. Deaths from Alzheimer's Disease — United States, 1999–2014. *MMWR Morb Mortal Wkly Rep* 2017;66:521–526. <https://www.cdc.gov/mmwr/volumes/66/wr/mm6620a1.htm>
- <sup>9</sup> James BD, Leurgans SE, Hebert LE, Scherr PA, Yaffe K, Bennett DA. Contribution of Alzheimer disease to mortality in the United States. *Neurology* 2014;82:1045–50
- <sup>10</sup> Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. *JAMA*. 2014;311(10):1052-1060.
- <sup>11</sup> Roth DL, Fredman L, Haley WE. Informal Caregiving and Its Impact on Health: A Reappraisal From Population-Based Studies. *The Gerontologist*. 2015;55(2):309-319.
- <sup>12</sup> Center for Medicare and Medicaid Services. Chronic conditions among Medicare beneficiaries: 2015. [https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/Chartbook\\_Chrtb.html](https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/Chartbook_Chrtb.html)
- <sup>13</sup> Phelan et al. A Systematic Review of Intervention Studies to Prevent Hospitalizations of Community-dwelling Older Adults with Dementia. *Medical Care*. 2015;53(2), 207)
- <sup>14</sup> Alzheimer's Association and Centers for Disease Control and Prevention. The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013–2018: Chicago, IL: Alzheimer's Association; 2013. <https://www.cdc.gov/aging/pdf/2013-healthy-brain-initiative.pdf>



**Prepared Statement of  
Teresa Osborne, Secretary  
Pennsylvania Department of Aging**

**United States Senate  
Special Committee on Aging**

*Changing the Trajectory of Alzheimer's: Reducing Risk, Detecting  
Early Symptoms, and Improving Data*

Thank you, Senator Collins and Senator Casey for the opportunity to testify at this important hearing that is focused on changing the trajectory of Alzheimer's by reducing risk, detecting early symptoms, and improving data. It is a true privilege to be before you and this committee, as advocates from across the country gather here in Washington, D.C. to advance policies intended to improve the lives of all individuals affected by Alzheimer's disease.

As Secretary of Aging for the Commonwealth of Pennsylvania, I have the honor of serving at the pleasure of Governor Tom Wolf, who has made it a priority that we uphold the provisions of the Older Americans Act, which calls us to serve as visible and effective advocates for older Americans. In my role, I have the awesome opportunity to meet with and listen to individuals and families in communities throughout Pennsylvania, and I have seen firsthand how the Older Americans Act and the aging services network supports the values that we all share: helping older adults and persons with disabilities live and age well in the setting of their choice for as long as possible; developing and implementing a person-centered approach to care; promoting inclusion and empowering independence and self-determination; protecting the most vulnerable among us from all types of abuse, neglect, and exploitation; and providing basic respite care and other supports for caregivers so that they are able to take care of loved ones in their homes and communities, which is what each of us desires and deserves.

Of the nearly 13 million citizens who call Pennsylvania 'home', 3 million are age 60 and over. By the year 2020, 1 in 4 Pennsylvanians will be 60 years of age and over. Within our 67 counties of the commonwealth there are 52 local area agencies on aging. Under the Older Americans Act, these area agencies on aging serve as "on-the-ground" organizations charged with helping vulnerable older adults live with independence and dignity in their homes and communities. Each area agency on aging plays a key role in helping us plan, develop, coordinate, and deliver a wide range of long-term services and supports to older adults in communities throughout Pennsylvania.

To this end, and for our purposes today, I will focus my attention specifically on the estimated 280,000 Pennsylvanians who are living with Alzheimer's disease, and will clarify that the number is closer to 400,000 when we add in those living with related disorders. Furthermore, nearly 675,000 Pennsylvania caregivers are providing a total value of \$9 billion dollars in unpaid care to loved ones with dementia. Alzheimer's disease is the 6<sup>th</sup> leading cause of death in the

country, as well as in the commonwealth of Pennsylvania. All told, one in twelve Pennsylvania families are affected by Alzheimer's disease and other related disorders.

For far too many years, Alzheimer's disease has been treated as an "aging" issue. Yet, it's impossible for us to continue to ignore the public health consequences of a disease that someone in the United States develops every 66 seconds. Alzheimer's is the nation's most expensive disease, costing \$277 billion in 2018, including \$186 billion in costs to Medicare and Medicaid. It is the only leading cause of death in the United States without a way to prevent, cure, or even slow its progression. There are no survivors. Like many, if not most, who gather in Washington, D.C. today, I am passionate about working to end this disease, as I have witnessed first-hand the human consequences of this disease on countless Pennsylvanians and their families, including members of my own family.

In Pennsylvania, we believe the Alzheimer's trajectory can be influenced and changed by increasing our country's commitment to Alzheimer's research, building an Alzheimer's public health infrastructure, and leveraging Older American's Act services to bend the cost curve on the growing costs associated with caring for individuals with Alzheimer's disease.

With much appreciation, Congress continues to fund Alzheimer's research at the United States National Institutes of Health. This Congressional commitment to fight against Alzheimer's is further demonstrated through the National Institute on Aging (NIA), a division of the National Institutes of Health, which funds Alzheimer's Disease Centers at major medical institutions throughout the United States. Every day, researchers at these Centers focus their efforts on translating research advances into improved diagnosis care for individuals with Alzheimer's disease. Moreover, these researchers are incredibly motivated to identify any and all activities that can help to diagnosis, treat, prevent and cure Alzheimer's. For those diagnosed and their families, thirty-two Alzheimer's Disease Centers in twenty-one states, offer help and hope by also providing information about the disease, services, and resources; offering opportunities for volunteers to participate in clinical trials, studies, and patient registries; and connecting those diagnosed and their families with support groups and other special programs.

Potentially ground-breaking research is being conducted at two NIA-funded Alzheimer's Disease Research Centers in Pennsylvania, including the Penn Memory Center, which is located in Philadelphia at the University of Pennsylvania, and the University of Pittsburgh

Alzheimer's Disease Research Center in Allegheny County. These remarkable Pennsylvania-based Alzheimer's Disease Research Centers collaborate with other academic research groups, along with pharmaceutical, biotechnology, and diagnostic companies. They play a substantial role in advancing knowledge and developing new treatments and diagnostic technologies; and help to well position Pennsylvania to build upon its strong base in research and technology, not only in the pursuit of improved care and treatment for people with Alzheimer's, but also as an engine for economic development.

Pennsylvania's current infrastructure is thus in perfect alignment with the country's need to further invest in a nationwide Alzheimer's public health response that will promote better treatment and care for those living with Alzheimer's. The BOLD (Building Our Largest Dementia) Infrastructure for Alzheimer's Act is proposed to establish Alzheimer's Centers of Excellence across the country by funding state, local and tribal public health departments to increase early detection and diagnosis, reduce risk, prevent avoidable hospitalizations, reduce health disparities, support the needs of caregivers, and support care planning for people living with the disease. These important public health actions are already embedded in both Pennsylvania's State Plan on Aging, which is required under the Older Americans Act, and our State Plan on Alzheimer's Disease and Related Disorders, which is dedicated to helping persons with Alzheimer's to age in place in their homes, and to delay costly institutionalization care for as long as possible. Due to the strong foundation already laid, we believe that Pennsylvania is well-prepared and perfectly positioned to boldly take action by hosting an Alzheimer's Center of Excellence.

Further evidence of this preparation is the fact that while the first national plan to fight Alzheimer's disease was presented in May 2012 at the Alzheimer's Research Summit, Pennsylvania's call to action occurred in February 2013 when then Governor Corbett signed an Executive Order establishing the Pennsylvania Alzheimer's Disease State Planning Committee. This committee was charged with developing a state plan to address the growing Alzheimer's disease epidemic in the commonwealth. In crafting a plan for Pennsylvania, the committee heard from representatives from the diverse communities that comprise our state. Pennsylvania is the nation's sixth most populous state--our residents live in urban, suburban, rural, and frontier communities. Pennsylvania is the second most rural state in the nation. According to the U.S. Census Bureau, nearly 27% of the state's residents lived in 48 rural counties in 2010. By 2030, this number is projected to increase by 3%. Moreover, the committee learned that in order

to address the enormous breadth of what is included in a statewide endeavor to help fellow Pennsylvanians living with and caring for someone with Alzheimer's disease, partnerships are necessary for our communities to become places to live and age well. Ultimately, the committee developed seven overall recommendations that were designed to mobilize the commonwealth's response to the current and anticipated increase in the prevalence of Alzheimer's disease and related disorders in Pennsylvania.

Unveiled in February 2014 as the Pennsylvania State Plan on Alzheimer's Disease and Related Disorders (ADRD), its seven overall recommendations are:

1. Improve awareness, knowledge, and sense of urgency about medical, social, and financial implications of ADRD.
2. Due to the magnitude of the ADRD epidemic, identify, and where possible, expand financial resources to implement this plan through federal, state, foundation, private, and other innovative funding mechanisms and partnerships.
3. Promote brain health and cognitive fitness across the life cycle from birth onward.
4. Provide a comprehensive continuum of ethical care and support that responds to social and cultural diversity, with services and supports ranging from early detection and diagnosis to end of life care.
5. Enhance support for family and non-professional caregivers and those living with ADRD.
6. Build and retain a competent, knowledgeable, ethical, and caring workforce.
7. Promote and support novel and ongoing research to find better and effective cures, treatments, and preventative strategies for ADRD.

Under the Wolf Administration, we have continued to evaluate progress made, while also assessing and determining where to focus current and future efforts. Regularly, we find ourselves pivoting back to public-private partnerships serving as the best way to strengthen the ongoing need for research in pursuit of a cure. Simultaneously, we recognize that we need to put into practice what we know about prevention, while enhancing the quality of care and support for those living with Alzheimer's and their families and friends who support them in their Alzheimer's journey. In partnership with the Alzheimer's Association, Pennsylvania has been laser-focused on helping those facing memory problems and other cognitive deficits which affect daily life, to first talk with their physician. We then work with physicians to fast track their patients immediately following a diagnosis to an easy-to-use Next Step Direct Connect referral program. We recognize that once there is a dementia diagnosis, it is never too early or too late



for a referral to the Alzheimer's Association's Helpline, where family care support is available 24 hours a day, seven days a week. Via early detection, patients and their families can receive the maximum benefit from available treatments for dementia and related conditions, and with a referral to the Alzheimer's Association, they can more easily create a care plan to address immediate needs, as well as get referrals to resources for assistance with current and future planning.

Pennsylvania's investment in its State Plan on Alzheimer's Disease and Related Disorders and its partnership with the Alzheimer's Association was further strengthened last month, when Governor Wolf capped off Older Americans Month by announcing the formation of Pennsylvania's Alzheimer's State Plan Task Force. The 15-member task force was created to take the lead role in implementing and championing the goals and recommendations of Pennsylvania's State Plan for Alzheimer's Disease and Related Disorders. We recognize that the toll of this disease extends beyond those affected to their families, friends, and communities, and believe that with task force members who are passionate and engaged partners from geographically and personally diverse backgrounds, Pennsylvania's fight against Alzheimer's will have immediate, positive, and lasting impacts. Task force members will focus on working with local organizations, entities, advocates, and other stakeholders to identify and share best practices that support the goals and overall success of the plan, will lead efforts to review and revise the State Plan, will develop and facilitate the actions needed to carry out the State Plan, will pursue research and review any other issues that are relevant to Alzheimer's disease and related disorders, will assist in the planning of our Annual Alzheimer's Disease and Related Disorders Forum, and will assist in the development of an annual update to the State Plan. Two prominent Alzheimer's Association advocates, Bob Marino and Clay Jacobs, are serving on the task force, which further demonstrates our commitment to work together as unrelenting advocates for public policy at all levels of government that advances research and improves access to care and support services for persons with Alzheimer's and their caregivers.

Lastly, from our lens at the Pennsylvania Department of Aging, whenever we talk about health care and the elderly, we immediately refer to three landmark federal programs that were created fifty-three years ago: Medicare, Medicaid, and the Older Americans Act. While Medicare and Medicaid began as basic health care programs, over the years they have evolved where they now provide Americans with improved access to quality and affordable health care coverage. Notwithstanding, in today's challenging times, it's the Older Americans Act that is enabling the

aging network to play a central role in bending the cost curve on the growing costs of two very large federal entitlement programs.

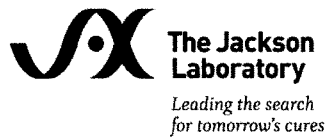
Every day, in communities across the country, State Units on Aging, in partnership with their network of local area agencies on aging, through the provision of Older Americans Act services, help older Americans remain healthy, work longer, stay connected with their community, avoid hospitalizations or re-hospitalizations, and defer altogether or transition from nursing homes. In addition, the Older Americans Act also encourages its aging network to provide access to evidence-based health promotion and disease prevention programs, such as chronic disease self-management, healthy steps for older adults, 10 keys to healthy aging, and healthy steps in motion, along with immunization, vaccine and health screenings, all of which helps to reduce health care costs for older adults with chronic conditions, which are the biggest drivers of Medicare spending. Moreover, experience has shown that the home and community-based services provided under the Older Americans Act, such as personal care assistance, support for caregivers, nutritional programs, and transportation services, when targeted properly and delivered effectively, reduce other areas of concern that drive costs, such as hospital readmissions.

Older Americans Act services provides critical federal funding and the necessary infrastructure to deliver vital support programs and social services to seniors throughout the country, including those with Alzheimer's disease and related disorders, as well as their millions of unpaid family caregivers, through programs such as the National Family Caregiver Support Program, which supports low-income seniors with dementia. Since its enactment, the Older Americans Act has kept millions of older Americans healthy, independent, secure, and able to live at home for as long as possible. For the past five decades, Older Americans Act services have grown and adapted to many of our nation's changing needs. In every setting and through each advancing year, Older Americans Act services support health, foster independence, and promote dignity. The programs authorized by the Older Americans Act have never been more important to individuals, to families, and to communities throughout the country. Congress's continued support and reauthorization of the Older Americans Act reflects its commitment to the health and well-being of the aged and aging in America. It also furthers its support of the aging network and its capacity to rebalance the long-term care system by building on the non-Medicaid community-based support system embodied in the Older Americans Act. These are the steps necessary to promote prevention, improve treatment, and ensure access to services for those living with Alzheimer's and the caregivers who journey with them.

**Prepared Statement of Gareth Howell, Ph.D.  
Associate Professor, The Jackson Laboratory,  
Bar Harbor, Maine**

Changing the Trajectory of Alzheimer's: Reducing Risk,  
Detecting Early Symptoms, and Improving Data

Testimony to Members of the  
Senate Special Committee on Aging



Good afternoon Chairwoman Collins, Ranking Member Casey, and members of the committee. Thank you for the invitation to be here today and for your work in support of Alzheimer's disease and dementia research. My name is Dr. Gareth Howell and I am an Associate Professor at The Jackson Laboratory in Bar Harbor, Maine and co-Principal Investigator of the MODEL-AD Center.

I am extremely grateful for the opportunity to provide this testimony to the committee. Your leadership on the Aging Committee, and in Congress, is key to the search for treatments for this terrible disease. In particular, we appreciate the committee's support the committee's support of legislation including the National Alzheimer's Project Act, authored by Senator Collins. The research community is also appreciative of the Alzheimer's disease bypass budget and the recently approved increase of an additional \$414 million for Alzheimer's and dementia research. I am confident science will overcome Alzheimer's disease; the question is when? Your continued engagement with the research community is vital as we seek to better diagnose, prevent and treat Alzheimer's disease as soon as possible.

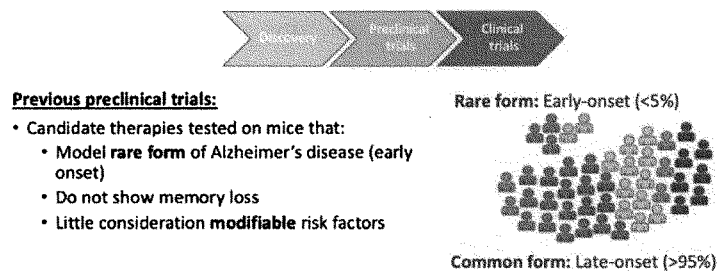
The Jackson Laboratory is an independent, nonprofit, 501(c)(3) tax exempt research institute that strives to discover precise genomic solutions for disease and empower the global biomedical community in its shared quest to improve human health. The Laboratory maintains its main campus in Bar Harbor, Maine, and maintains other locations in Farmington, Connecticut, and Sacramento, California. The Bar Harbor campus is dedicated primarily to mammalian genetics research and central operations, while the Farmington campus, also known as the The Jackson Laboratory for Genomic Medicine, is dedicated to human genetics and genomics research. The Sacramento includes state-of-the-art vivarium for breeding and distribution of mouse models as well as laboratory space for in vivo research services.

My scientific research career began as a geneticist at The Sanger Institute in Cambridge, UK where I did my PhD in comparative genomics – identifying errors in genes responsible for human diseases and identifying their counterparts in the mouse genome. Being able to study the genes in mice allowed us to uncover potential therapeutic treatments. After my PhD, I moved to The Jackson Laboratory in Bar Harbor, Maine. Aging research has been a key area of investigation at JAX for many years. However, in the last five years, we have established a vibrant Alzheimer's disease research program that includes more than 40 scientists led by myself and Drs. Gregory Carter, Catherine Kaczorowski and Kristen O'Connell. We aim to identify genetic factors that drive both susceptibility and resilience to AD, as well understanding how modifiable risk factors (e.g. diet/physical activity) and comorbidities (obesity, diabetes, heart disease) contribute to AD.

Ultimately, working with the larger scientific community in the US and worldwide, we hope to leverage these findings to identify and test novel therapeutic targets. My lab's goal is to identify the earliest stages of Alzheimer's disease and dementia, since targeting these provides the greatest opportunity for therapeutic intervention. It is incredibly challenging to identify these stages in human patients since they occur before any recognizable symptoms emerge. However, this is where animal models of human diseases come in. An animal model is a representation of a human disease and we can use

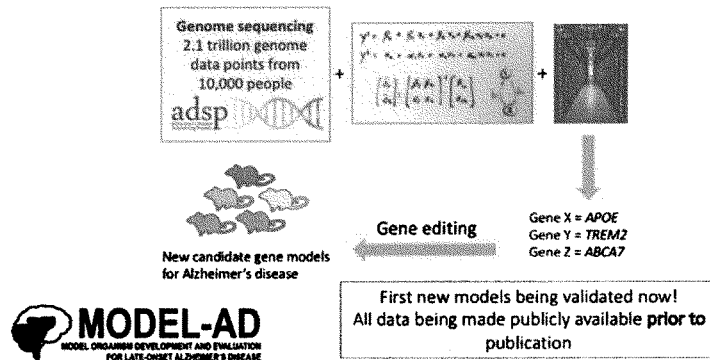
animal models to precisely define key stages of a disease – particularly the earliest stages. Mice share 95% of their genes with humans and so at JAX we focus on building accurate representations of human disease in mice. We then use a variety of genetic and genomic approaches to identify genes and proteins that are key drivers of disease during pre-symptomatic stages. These drivers are the targets for developing treatments that can then be tested in the mouse model. For example, the power of the mouse for treating a human disease was highlighted recently for spinal muscular atrophy (SMA), a disease characterized by muscle weakness and atrophy. A mouse model for SMA was created at JAX, a treatment tested in the mice, and following successful clinical trials, the first treatment to treat children and adults with SMA was approved by the Food and Drug Administration in December 2016. We can also use mice for incorporating non-genetic risk factors – such as diet, physical activity – and other diseases that increase risk for AD – such as cardiovascular disease and diabetes. The expectation is that preventative measures will be more effective than interventions. Therefore, encouraging lifestyle changes in the young and the middle aged should also be a key focus.

Sadly, many clinical trials for Alzheimer's disease have not been successful. There is a multitude of reasons why these trials have not been successful including targeting severe stages of AD, rather than early or presymptomatic stages. Unfortunately, for Alzheimer's disease, and other dementias, there is also a major bottleneck in searching for treatments. There is no single mouse model for the most common form of Alzheimer's disease – known as sporadic or late-onset Alzheimer's disease (**Fig. 1**).

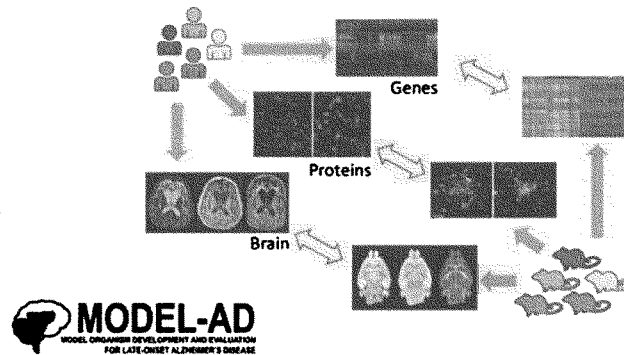


**Fig. 1:** Clinical trials for therapies for Alzheimer's disease have not worked.

Until mice are developed that reproduce defining features of Alzheimer's disease, the power of the mouse will not be fully realized. Therefore, I am really excited to be a part of MODEL-AD, a collaboration between Indiana University, JAX, Sage Bionetworks and University of California Irvine, that was established through generous funding from the National Institute on Aging (NIA) in the fall of 2016. We are charged with creating new mouse models for Alzheimer's disease (**Fig. 2**), staging and matching the changes we see in the mice to those seen in humans (**Fig. 3**), and testing potential new therapies.



**Fig. 2: Finding new gene combinations for Alzheimer's disease.** All animal models created by MODEL-AD are based on large genomic datasets from human studies (e.g. Alzheimer's disease sequencing project (ADSP)). Combinations of gene changes are 'edited' into the mouse genome to determine how they contribute to AD risk.



**Fig. 3: Matching Alzheimer's disease in humans and mice.** All animal models are assessed for AD-relevant outcomes using similar techniques to those used to diagnose AD in humans. This will greatly improve the translatability of our findings, in particular, the relevance of testing potential therapeutic compounds prior to a clinical trial.

It is very rare to have a Center that is capable of both generating the mouse models and testing potential new treatments. Significantly, we also have strong links with pharmaceutical companies, including Eli Lilly and Pfizer, aiming to close what has been a significant gap between academic research findings and translation to clinic.

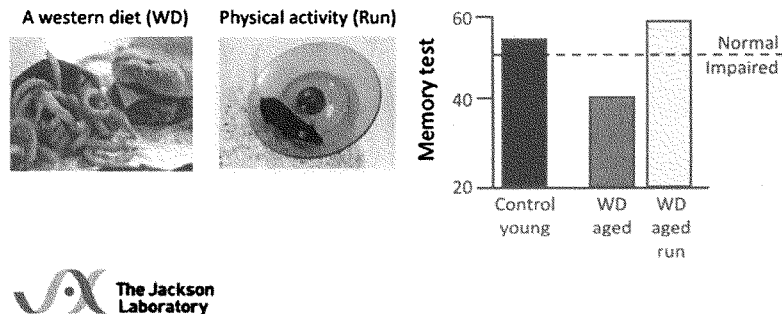
I believe the structure of the MODEL-AD Center maximizes the chances of our success. The collaborations that occur within the center are successful because the diverse group of researchers with different specialties are banded together, sharing information in real time with each other, allowing us to build on each others research. This type of approach would benefit from an overall public health approach. The amount of data generated by researchers is coming at a fast pace and we would benefit from data clearinghouses to help us crunch it. Based on the recommendations of program officers at the NIA, MODEL-AD is made up of groups of scientists, or 'cores', that are allowing us to generate mice that are most likely to show similar changes to those seen in Alzheimer's disease. We have a **Bioinformatics Core** – which is working with clinician scientists to search through all the data generated from human Alzheimer's disease patients to identify specific genes that may be altered to increase risk for the disease. We have a **Disease Modeling Project** that is introducing those same genetic errors into the mouse equivalent of the human gene to determine how similar the outcomes are to the human condition. We have a **Preclinical Testing Core** that will then use those more precise mouse models of human Alzheimer's disease to assess new therapies before they can be tested in the clinic. All our work is overseen by a group of expert scientists from academia and pharma to ensure our work stays focused on finding new treatments. Most importantly, all mouse models will be made widely available to the scientific community – something JAX has been doing for over 50 years – and all data will be made publicly available through a specially developed web portal designed that was created and is managed by Sage Bionetworks.

We are joining a new era in research where individuals are no longer working behind closed doors to seek the best solution. We are combining our strengths and working together through the concept of open science to accelerate the discovery of cures for Alzheimer's disease. The open science approach focuses on early, broad sharing of research resources with the dual goals of improving transparency and reproducibility in the research process and of ensuring publicly funded resources are made broadly available for reuse across the research community. The NIA has made significant investments into the application of open science for advancing Alzheimer's disease research – first by mandating the use of open science approaches to all scientists working on target discovery within the Accelerating Medicines Partnership in Alzheimer's disease and then by expanding the open research community to work across multiple consortia. We are proud to have MODEL-AD join this effort.

Much of the data that is being generated by large consortia should be considered a resource as much as research findings. Within MODEL-AD, we already benefit hugely from the open science policy instigated by the NIH. Much of the data we are using to predict which mice to make is freely available. We then create and extensively characterize these new mouse models for AD. However, there are always more ways to characterize these mice and also to use them to ask specific questions like "Is my gene or biological process involved in the progression of AD?" or "would my drug slow or prevent AD?". By making these mice and all data available at the earliest opportunity allows for these questions to be asked more quickly and effectively by the wider scientific community.

Our Center aims to create more than 40 new mouse models for Alzheimer's disease and test at least 5 new compounds for their potential to prevent, slow or cure Alzheimer's disease. Although we are only nine months into this five-year project we have made a great start. The first mice, carrying the greatest genetic risk factors for human Alzheimer's disease, have been created and are available to the research community. We have searched through billions of data points and already identified more than 10 new genetic errors that we are testing in mice. We have established procedures by which potential new compounds can be tested in the mice. Obviously, we have a lot of work to do but we are encouraged by the data and confident that we can make a difference.

The MODEL-AD center is already benefiting my research program and Alzheimer's disease research at JAX. My interest centers on the interplay between the immune system and blood vessels in dementia. Changes in immune cells and blood vessels in the brain may occur in as many as 90% of all dementias (including Alzheimer's disease, mixed dementia and vascular dementia). These damaging events can be influenced by genetic changes or by our lifestyle, particularly what we eat and whether we exercise. In my lab, we are studying how genetics and lifestyle factors contribute to blood vessel damage and immune changes. Data from my lab and many others, support modifying our lifestyle, such as eating healthier and exercising more, to reduce risk for dementia (Fig. 4). Our work showed that regardless of the diet they consumed, mice that exercised from young to middle or old age remained cognitively normal. Further, using a variety of different assays, we confirmed that the brains of the aged mice were indistinguishable from brain of young mice.



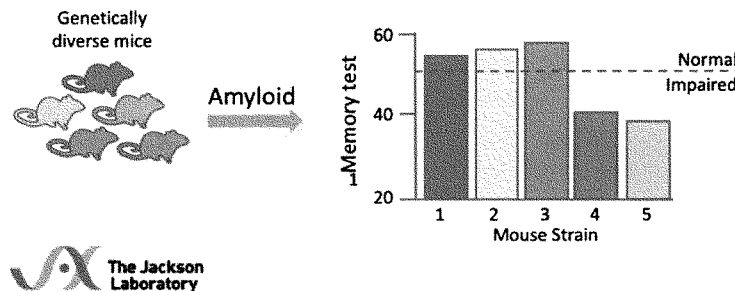
**Fig. 4: Targeting modifiable risk factors to decrease incidence of Alzheimer's disease.** Mice fed a diet similar to that consumed in the western world became obese and showed memory loss by midlife. However, these damaging effects could be overcome by regular exercise. These data support human studies that suggest changes to lifestyle would significantly reduce Alzheimer's disease cases.



Ultimately, we hope to stop or delay the onset of dementia by preserving the health of blood vessels, even in the face of damaging processes such as amyloid accumulation. We have already incorporated mouse models that were created as part of MODEL-AD into our work and aim to begin to test potential new therapies targeting blood vessel health in the coming months.

A second major interest in my lab that is benefiting from MODEL-AD is whether we can use the eye as a tool to track risk and progression of dementia. The eye is a window to the brain; the retina (where light-sensitive cells process information that is sent to the brain via the optic nerve) is essentially a piece of brain outside the skull that may be susceptible to some of the changes we see in dementias such as Alzheimer's disease. The eye is much easier to monitor than the brain. Although this is somewhat controversial at this time, if we can identify changes in the eye that relate to early, pre-symptomatic changes in the brain, we may be able to diagnose and treat those at earliest stages of dementia through simple eye exams. We are using the mouse models created by MODEL-AD to generate important preliminary data to seek additional funding to fully explore the potential of using the eye as a diagnostic tool.

Finally, a commonly forgotten aspect of mouse studies is that genetically diverse mice exist. These have not been well utilized to study Alzheimer's disease and related dementias. In general, most studies have been performed on one strain of mouse. This would be like studying a single human being over and over again. At JAX, we have access to the latest in genetically diverse mouse strains and are incorporating them into our research programs. Data from multiple labs at JAX show that if you induce amyloid deposition into different mouse strains, some develop dementia-like memory loss, while others do not (Fig. 5). This mimics the human population, where some individuals with amyloid deposition develop dementia, while others do not. We are now using these new mouse strains to determine the genetic factors that control amyloid-induced dementia. We anticipate finding new genes and pathways that can be targeted as potential treatments for AD and related dementia.



**Fig. 5: Genetic context determine susceptibility to Alzheimer's-like memory loss.**

Genetically diverse mouse strains capture a similar degree of variant as seen in the human population. Different mouse strains show different outcomes after they have been genetically modified to deposit amyloid. Some are resilient to memory loss (red, yellow and green bars), while others are susceptible to memory loss (blue and orange bars). We are now using genetic and genomic approaches to determine the genes driving these different outcomes. This work will lead to the identification of new therapeutic targets.

In summary, research at The Jackson Laboratory, and collaborations such as MODEL-AD aim to deal with a critical bottleneck – namely the creation of mouse models that more faithfully reproduce human Alzheimer’s disease. These models will be a vital piece in the puzzle to develop strategies to prevent, slow or treat Alzheimer’s disease. I express my thanks to the Committee for this opportunity and for its continued support of Alzheimer’s disease research.

**Useful resources**

For more information about MODEL-AD: <https://model-ad.org/>

For information about Alzheimer’s disease research at JAX see the following resources:  
Alzheimer’s disease: <https://www.jax.org/explore-by-topic/neurodegenerative-disease/alzheimers-disease>

Breaking the bottleneck in Alzheimer’s drug development: <https://www.jax.org/news-and-insights/2017/january/breaking-the-bottleneck>

MODEL-AD at JAX: <https://www.jax.org/research-and-faculty/tools/alzheimers-disease-center/alzheimers-disease-precision-models-center>

**Prepared Statement of Cheryll Woods-Flowers Family Caregiver,  
Mount Pleasant, South Carolina**

Chairman Collins, Ranking Member Casey and members of the Committee. Thank you for the opportunity to testify about my experiences as a caregiver for my late father. I hope my story will bring more awareness to this awful disease, called Alzheimer's.

My father, Richard Allen Novak Sr., passed away in February after living with Alzheimer's disease for nearly 16 years. When he was 18, my dad left his home in Wisconsin to join the U.S. Navy, which led him to Charleston, South Carolina where he would meet and fall in love with my mom. Dad worked hard throughout his career in the Navy and after retiring, he worked in Civil Service, retiring in 1988, and then started a successful woodworking business. He was always willing to help anyone who needed him, sometimes without accepting payment. He will be remembered for his love of dogs, people, his amazing Christmas light display that always drew lines of cars, and his love for his family including his six children, 11 grandchildren and 14 great grandchildren.

Before my dad was diagnosed with Alzheimer's disease, it was not something that my family knew much about. My mom started noticing that dad seemed to be having trouble remembering where he left things; he was taking longer with errands and kept forgetting things he was supposed to be doing. In 2003, my parents took a trip to Florida, which they had done many times before, dad left at 8 a.m. to get a tire fixed on the car, and at about 4 p.m. mom called us and said they could not find him. When we found him, he had been crying, had not eaten and did not have any money. It was truly an eye-opening experience. After that, we knew we had to get help. We took him to a specialist at the Medical University of South Carolina and after a few cognitive tests; he was diagnosed with Alzheimer's. He was on Aricept and Namenda, both of which he continued to take until the end. He was diagnosed at age 70 and every day we lost a little bit more of him, including the last 5 years when he did not recognize his children, grandchildren or other family members. Though he did not know us, he continued to express love to each person he encountered, showed gratitude when things were done for him and we were so happy to be around him.

In a way, we were lucky that my dad was diagnosed so early in the disease. According to the Alzheimer's Association, only about half of individuals living with Alzheimer's have been diagnosed. When people are diagnosed early in the disease, they have time to work with their family and physician to engage in care planning, talk through financial decisions, and discuss support services. My dad's early diagnosis gave us that time to talk through decisions, start interventions like medications to mitigate symptoms, and gave him a better quality of life because we knew what we were up against.

I believe it is important to make the public and health care professionals aware of the early signs of Alzheimer's disease. There needs to be a greater nationwide public health effort and infrastructure in order to increase early detection and diagnosis. Legislation like the BOLD Infrastructure for Alzheimer's Act will help to do that. It would create an Alzheimer's public health infrastructure across the country that would look to tackle certain Alzheimer's public health issues like increasing early detection and diagnosis. BOLD would accomplish these goals by creating Centers of Excellence across the country that would educate the public, public health officials and health care professionals on Alzheimer's, brain health and health disparities. It would work with State, local and tribal public health departments to implement interventions to increase early detection and diagnosis.

After dad was diagnosed, my sister, Theresa, and I were named his Conservator and Guardian. We were his primary family caregivers. We were only able to do that because we lived nearby and we had the funds to keep him home as long as possible. We sold the house that my dad bought 55 years ago in order to be able to pay for his care. About 3 years ago, we got to the point where it was time for him to live in an assisted living facility. We found a great facility nearby but it certainly did not come without significant expense. The average estimated lifetime cost of care for an individual living with dementia is over \$340,000. In 2017, 16.1 million family members and friends provided 18.4 billion hours of unpaid care to people with Alzheimer's and other dementia at an economic value of over \$232 billion.

I do not believe there is a complete understanding of the cost of Alzheimer's disease on our society. Since 2011, Congress has worked in bipartisan fashion to nearly quadruple the funding for Alzheimer's and dementia research at the National Institutes of Health (NIH). We've made great strides but there is still so much further to go. Alzheimer's disease is the most expensive disease in America. In 2018, Alzheimer's and other dementia will cost the Nation \$277 billion and by 2050, those

costs could be as high as \$1.1 trillion. Research dollars are critical to solving this crisis that devastates families and will impact our economy.

I've always believed that it is never enough to sit around and wait on someone else to do something. If not me, then who? About 4 years ago, I became an advocate with the Alzheimer's Association. I have met with my congressman to talk to him about making Alzheimer's research, care and support a national priority. Every year since 2014, I participate in the Walk to End Alzheimer's because I want to be part of the effort to eradicate this disease.

These last few days, I joined more than 1200 advocates from across the country to make a difference here in Washington. We are here to advocate for the 5.7 million Americans living with Alzheimer's today, to raise awareness of the disease and to push for more research funding. Alzheimer's is the only leading cause of death in the U.S. that cannot be prevented, cured, or even slowed, but through medical breakthroughs we're working together to change that. I am here because I promised my dad that I would be his advocate and voice as long as I am able to and with hope that my children and grandchildren will not have to think about these issues because a cure will be found.

As a caregiver and advocate, I am respectfully asking Congress to continue to make Alzheimer's research a priority and pass the BOLD Infrastructure for Alzheimer's Act to help other families get diagnosed early.

This is my first father's day without my dad. Thank you for listening to our story and for all you have done. Please continue to join us in the fight to end Alzheimer's once and for all.

