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ALZHEIMER'S DISEASE: A BIG SKY APPROACH TO A NATIONAL CHALLENGE

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ALZHEIMER'S DISEASE: A BIG SKY APPROACH TO A NATIONAL CHALLENGE

WEDNESDAY, AUGUST 13, 2014

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

The Committee met, pursuant to notice, at 10 a.m., in the South Park Senior Center, 901 South 30th Street, Billings, Montana, Hon. John E. Walsh, presiding.

Present: Senator Walsh.

OPENING STATEMENT OF SENATOR JOHN E. WALSH, COMMITTEE MEMBER

Senator WALSH. Good morning. I want to welcome everyone to this Senate Special Committee on Aging field hearing. I thank all of you for taking time out of your busy schedule to be here with us today and to discuss this very important topic.

I would like to start by thanking Dolores Terpstra and the board of the South Park Senior Center for your generosity in sharing this space. Thank you very much.

I would also like to thank Bea Ann Melichar, who is the Executive Director of the Adult Resource Alliance, and her staff, for all your work. Bea, thank you very much.

I would also like to thank the Alzheimer's Association, and especially the Montana Director, Heidi Gibson—where is Heidi at? All right. Heidi, thank you for all the help that you have done to provide for this field hearing. The Alzheimer's Association does great work to educate and support families dealing with this difficult disease. They will be hosting a number of events across the State the next month to raise awareness and money to help find a cure, so, if you are able to participate in a Walk to End Alzheimer's event, I encourage you to do so.

I will start off with a little bit of housekeeping for this hearing. I want everyone here to be part of the conversation. My staff have distributed comment cards that we hope you will use to ask your questions for our witnesses. Just fill it out during this hearing and pass it to one of my staff. If my staff would please raise your hands so you can see who they are. We may not be able to get to all the questions during this hearing, but I will make sure your questions for the witnesses are submitted for the record so they can be answered after the hearing.

We have a great line-up of witnesses with us today and I am looking forward to hearing from each one of you. Thank you for being here with us.

Dealing with Alzheimer's disease is a tremendous challenge. This is especially true in a rural State like Montana, where great distances can make it difficult to access community resources, so, it is crucial that we tackle the challenge head-on. Perhaps the most important goal of this field hearing is to raise awareness about the disease and to help reduce the stigma associated with Alzheimer's.

Alzheimer's disease is not a normal consequence of aging. It is estimated that half of all Americans with Alzheimer's disease have not been diagnosed, and, even among those who are diagnosed, many are not aware of the resources that are available to them when it is identified. If you or someone you love has Alzheimer's disease, I encourage you to get in touch with the Alzheimer's Association or your nearest Area Agency on Aging or another local support group for more information.

As our population ages, Alzheimer's disease is affecting more and more families across the State of Montana. Today, there are about 18,000 Montanans suffering from the disease. That number is projected to surge to around 27,000 in the next 10 years. This is clearly a growing problem that will only become more severe as our population ages.

Alzheimer's disease not only affects those with the disease, but it can cause a tremendous financial, emotional, and even physical toll for family members and other caregivers. There are about 48,000 people in Montana who care for someone with Alzheimer's disease or other dementias. Many of these unpaid caregivers cut back hours of work or quit their job in order to take on the responsibility of care. The Alzheimer's Association estimates that the value of unpaid care in Montana reached a staggering $677 million in 2013. That number is only rising, and it does not include the considerable emotional toll associated with the disease.

Research also shows that this disease particularly affects women. More than 60 percent of unpaid caregivers for someone with Alzheimer's disease are women. In addition, roughly two-thirds of people who develop Alzheimer's disease are women, so, this disease is equally harmful for both men and women, but women are disproportionately affected, largely because women live longer than men. Researchers have shown that older age is the greatest risk factor for this disease.

There is no doubt that this is a devastating disease. Symptoms develop slowly at first, but this disease steadily disrupts neural networks and overtakes a person's ability to perform basic tasks. This disease can literally cause the brain to shrink from a healthy three pounds to only one pound. In the process, people with Alzheimer's lose their ability to take care of themselves and can even lose the ability and capacity to recognize members of their own family. It is truly agonizing for loved ones in this situation.

I am working with my colleagues to strengthen the Federal commitment to Alzheimer's research and to help ensure that families have the resources that they need, and, I am proud to cosponsor the HOPE Act. This bill will ensure that families will have access under Medicare for not just a diagnosis, but also information and

other services to help navigate the disease. I have also cosponsored the Alzheimer's Accountability Act that would require the Director of the National Institutes of Health to submit an annual budget to meet the goal of preventing and treating Alzheimer's disease by the year 2025.

If you or a loved one is dealing with Alzheimer's disease, the message I hope you get from this field hearing is that you are not alone. There are many talented people in Montana who are working hard to educate and support caregivers.

One of those people here is here with us today in Billings, is Kathleen Burke. Both of Kathleen's parents served their country during World War II. They were decorated for their service in the European and African Theaters while stationed on a hospital ship in the Mediterranean Sea. Both, unfortunately, developed Alzheimer's disease. Kathy knows firsthand the tremendous challenges of caring for parents with Alzheimer's. Kathy has drawn from her experience to be an advocate in this community and she is a member of the Montana Alzheimer's Association Board of Directors. She is also the Caregiver Representative for the Montana Alzheimer's Working Group.

Today, I have asked the witnesses to limit their testimony to approximately five minutes each, and, with that, Kathy, we would like to hear from you. Thank you, Kathy, for being here.

STATEMENT OF KATHLEEN BURKE, DAUGHTER OF ALZHEIMER'S PATIENT, BILLINGS, MONTANA

Ms. BURKE. Good morning. Senator Walsh, individuals who recommended my participation, fellow panelists, audience members, thank you for this vital hearing. It was with a humbling sense of responsibility that I accepted the invitation to testify and bring a common face to Alzheimer's. I apologize ahead of time for speed-reading my testimony, but I am concerned about the time and do not want to miss points, especially educational ones.

My name is Kathleen Burke, and unfortunately, I have a family history of Alzheimer's and related brain disorders on both sides of my family for at least two generations. I helped my maternal grandparents when I was the only relative within 900 miles. I resumed caregiving when my mother, Shirley, was diagnosed with Alzheimer's in 2002, and my father, Jack, in 2010. My mother has been in a nursing home since January 2013 due to her Alzheimer's, now in its final stages. My father, who was on medication for his mild symptoms of Alzheimer's, died last September of pancreatic cancer.

I am honored to speak on behalf of the estimated 48,000 caregivers for the 18,000 Montanans currently diagnosed with Alzheimer's disease. The number of Alzheimer's patients is projected to increase in Montana by 50 percent by 2025. This is a startling forecast that we need to derail. When the government provides to Alzheimer's disease the level of support that has been given to cancer and heart disease research for the last 40 years, tremendous strides should also be accomplished for Alzheimer's.

The Alzheimer's Association provides this list of ten warning signs that can be used as a checklist to discuss concerns with medical providers. The signs are: Memory loss that disrupts daily life;

challenges in planning or solving problems; difficulty completing familiar tasks at home, at work, or at leisure; confusion with time or place; trouble understanding visual images and spatial relationships; new problems with words and speaking or writing; misplacing things and losing the ability to retrace steps; decreased or poor judgment; withdrawal from work or social activities; and changes in mood and personality. According to the 2014 Alzheimer's Disease Facts and Figures report, the personal difficulties that I will mention now are experienced by many Alzheimer's families.

Personality changes are common and can cause rifts in families if one does not remember that the disease adversely affects the person who used to know and relationships with them. I had to interrupt a class to deliver a message to a student about his parents in Great Falls. His Alzheimer's afflicted father had beaten his mother so severely that she was taken to the hospital and his father was arrested.

Mom put an appointment on the calendar, but did not know why. I took off work and found a salesman discussing plots in a veterans' section of a local cemetery, so my parents thought it was free for vets. I recognized the salesman, mentioned Mom's Alzheimer's, and explained that they would not be buying.

Mom was baking a frozen pizza for supper with the plastic wrap still on it. She said she always did it that way. Since it was no longer safe for her to cook and Dad did not know how, I had to solve the problem, which included in-home help costing $20 to $25 an hour in this area.

Mom was dropped off at a casino to play cards, but Dad remembered the wrong day, so her friends were not there. Rather than thinking to phone family members, she accepted a ride from a complete stranger to take her home. That was pretty shocking.

I would call Mom daily to ask if she had taken the pills set up for her and if she dressed. I started to find chewed gelatin pills in the garbage and on the floor. One day, she had two shoes of different colors, whereas another time she had on two right loafers. One night when I saw her limping and asked why, she did not know. I took off her shoe and found a sock crammed in the toe of her shoe. Dad was angry when I suggested he had to pay more attention when helping. His typical response was, "You do not understand."

When Dad had a brain abscess in 2007, I had to take Mom to work with me because I could not safely leave her by herself. It was difficult to find senior day care in Billings then. It is still limited, and may require a contract as opposed to meeting drop-in needs. The client has to be quite independent, but it is still cheaper than in-home care. My brother was fearful that my Dad's wanting to save money by taking care of Mom at home instead of using the nursing home would take a toll on Dad's failing health, which happens to caregivers.

Driving is a huge issue for Alzheimer's victims and their families. After twelve years of discussing it at caregiver meetings, I can remember only three people who gave up driving on their own, which was not the case for my Dad.

I had four experiences where Mom's increased confusion in unfamiliar surroundings, coupled with lack of Alzheimer's knowledge on the part of physicians and nurses, made for miscommunication and injury. This points out that Alzheimer's education is needed for everyone, including medical personnel, to meet the needs of these patients. Employers are another group for which education would improve understanding as to why employees need to be gone from work for caregiving for family members with Alzheimer's.

At the end of their 68th wedding anniversary celebration in the nursing home on July 4, 2013, Mom pushed Dad away when he bent over to kiss her goodbye, saying that her husband would not like that. It was difficult for me to see, but probably worse for him, since he would not talk about it. He was diagnosed with pancreatic cancer in August and did not visit her after that, knowing that she would not understand. It still hurt not to be able to tell her that her husband died of cancer and that his funeral was one day before her 91st birthday.

I considered retiring early so I could take care of Mom, but realized it is a 24/7 job for which there is not enough support. Her disease does not allow her to speak many words. She has eating challenges and is confined to a wheelchair. I visit her daily, but she usually does not realize who I am. I miss both my parents, the one who died physically and one who has almost died mentally.

In closing, thank you for letting me testify. With proper funding, I am looking forward to what can be done with Alzheimer's funding to prevent the terrible Montana forecast from becoming a reality.

Senator WALSH. Thank you, Kathy, very much.

Again, if you have questions for the panel, please pass them to my staff, and so what we will ask you to do is pass them over to the outside of the aisle, and my staff will collect the questions and we will make sure that they get asked, based on our timing.

Next, we will hear from George Carlson. George is the Director of the McLaughlin Research Institute, a nonprofit organization in Great Falls, Montana. George joined the McLaughlin Institute in 1988 and has overseen an expansion of the facility. Dr. Carlson is the 2014 inductee of the Montana Bioscience Hall of Fame. I am proud to have supported the McLaughlin Institute as Lieutenant Governor, and I will continue to support the Institute as a U.S. Senator for the State of Montana.

Dr. Carlson, you may begin. Thank you.

STATEMENT OF GEORGE CARLSON, PH.D., DIRECTOR AND PROFESSOR, McLAUGHLIN RESEARCH INSTITUTE, GREAT FALLS, MONTANA

Dr. CARLSON. Thank you, Senator Walsh, for providing me this opportunity to testify today on behalf of the McLaughlin Research Institute, and more importantly, on behalf of the people of Montana who are or will be afflicted by Alzheimer's and related dementing illnesses.

As you know, MRI is an independent, nonprofit research organization in Great Falls, and we conduct basic biomedical research to try to understand and, ultimately, prevent neurodegenerative diseases like Alzheimer's, Parkinson's, and related disorders. I thank you, Senator Walsh, for recognizing the looming national crisis that

will be caused by Alzheimer's and other dementias as our population ages.

The personal tragedy of dementia, that you just heard one example, cannot be fully comprehended by those whose family members have been spared. The suffering caused by Alzheimer's is reason enough to expand our efforts to prevent this illness. Unfortunately, the economic impact of dementing diseases also is immense.

Currently, according to the Alzheimer's Association, five million Americans and as many as 25,000 Montanans, if you include all dementias, are currently afflicted, with an annual financial cost to the country approaching $100 billion. By 2050, if nothing changes, as many as 16 million Americans could be affected, costing the economy $1.2 trillion. However, investment in research can bend this cost curve.

The effectiveness of biomedical research, which is funded largely by the National Institutes of Health, is unquestioned. Progress against cancer and heart disease over the past 50 years, to name only two examples, has been remarkable. For example, the impact of statins, which were developed based on fundamental basic research, on lowering the risk of coronary artery disease and heart attacks is well known.

In contrast, Alzheimer's was identified as a disease over 100 years ago and there are still absolutely no therapies capable of even slowing its inexorable course. It is telling that for every $28,000 the Federal Government spends on caring for patients with dementias, only $100 in Federal funds goes to support research on these disorders.

National Institutes of Health funding for Alzheimer's disease in 2013 was approximately $412 million, in comparison to $3 billion for AIDS research, $2 billion for cardiovascular disease, and $5 billion for cancer research. Support for research into all these diseases certainly is important, but the financial impacts of dementia is now greater than those of either heart disease or cancer.

On the positive side, the Obama administration has developed and is implementing a National Plan to Address Alzheimer's Disease. Unfortunately, funding is below the levels needed to accelerate progress toward the worthy goal of developing treatments that would prevent, halt, or reverse the course of Alzheimer's disease.

New approaches developed using mice, by MRI scientists and our collaborators, are being used to identify the earliest molecular changes in neurodegenerative diseases with the goal of finding markers in the blood that can indicate the presence of disease processes decades before clinical signs or symptoms appear. Although there is no treatment now, future therapeutic interventions are much more likely to be successful in the early stages of disease.

We also are beginning to understand the mechanisms for the prion-like spread of Alzheimer's disease pathology within the brain, potentially offering a new way to intervene in the disease process. The way disease spreads from one region of the brain to another is similar for Alzheimer's and Parkinson's disease as well as for chronic traumatic encephalopathy, which arises from traumatic brain injury and has been found in our troops returning from Iraq

and Afghanistan, so, this is a separate health crisis. The cost of the war does not end when the troops withdraw.

We understand more about Alzheimer's and other dementive disease than ever before, and our research is at a pivotal point. It is largely a matter of our elected representatives deciding that a cure is worth funding. At the same time that science is close to making a difference for people who will suffer dementing disorders, Federal funding for medical research is drying up.

We at McLaughlin are starting an exciting new initiative to speed up the translation of basic research findings into medical practice. We are collaborating with Benefis Health System in Great Falls to develop a Center for Aging Research and Memory Care, a unique partnership between an excellent community hospital and an internationally recognized research institution. This "center without walls" is not a place, but an exciting new initiative aimed at improving patient care now and in developing new avenues to search for ways to prevent disease.

As only one example, we will transplant stem cells from Alzheimer's patients into mice to watch the progression of disease in a living brain, providing a new tool to test potential therapies and giving us real hope for a cure.

With Federal support shrinking, the State of Montana stepped up with a grant of nearly $1 million in 2014 as seed money for this Center for Aging Research and Memory Care, and, I would like to thank you, Senator Walsh, for your support of this appropriation when you were Lieutenant Governor.

Americans also recognize that our Nation's global leadership in science is tenuous. Our leadership position will evaporate if policymakers shortchange government support for basic research. Unlike the U.S., countries like China and India are rapidly increasing their investments in science. MRI scientists are now receiving funding from India's National Center for Biological Sciences to help establish a mouse genetics facility and lab in Bangalore. While this international collaboration is exciting, I had never imagined that our research in Montana would be supported by funds from a developing country.

To maintain America's leadership in biomedical research, as well as find ways to prevent dementia and other devastating diseases, it is essential that talented young people pursue scientific careers. We at MRI have observed first-hand decisions by talented post-doctoral trainees discouraged by the downturn in grant application success rates to abandon basic research for careers that offer more security.

If Congress and the administration let funding for Alzheimer's and related disorders stagnate as inflation further eats away at its value, we will compromise progress at a time our health care system and the Nation can least afford it. Discoveries made at MRI and research organizations across the country have set us on the road to finding a way to prevent or cure dementing illness. It is essential to enhance Federal support for Alzheimer's disease research.

Thank you, Senator Walsh, for this opportunity to testify on behalf of the research community, and more importantly, on behalf of families affected by dementing illness.

Senator WALSH. Thank you, Dr. Carlson. Thanks for the work that you and MRI are doing. We really appreciate it.

Next, we have Dr. Patricia Coon. Dr. Coon is a geriatrician at the Billings Clinic and will serve as the Co-Chair of the Montana Alzheimer's/Dementia Work Group that will develop a State plan for dealing with this disease. She is also on the Board of Directors of the Billings Clinic Foundation.

Dr. Coon, the floor is yours.

STATEMENT OF PATRICIA JAY COON, M.D., BILLINGS CLINIC, AND CO-CHAIR, MONTANA ALZHEIMER'S-DEMENTIA WORK GROUP, BILLINGS, MONTANA

Dr. COON. Thank you. Good morning, Senator Walsh, fellow speakers, and members of the audience. As you have heard, I am Patricia Coon, a physician who has practiced geriatric medicine for nearly 30 years, the majority at the Billings Clinic in the frontier State of Montana. I also serve as the Co-Chair of the Montana Alzheimer's/Dementia Work Group, a statewide work group established this year with the goal of improving the lives of individuals in Montana with Alzheimer's and other dementias and to provide better support for the families and caregivers. It is an honor to be here to speak for that group today to discuss our efforts and the challenges we face caring for individuals with this devastating disease.

I think we have to—I always have to frame the dialog. Alzheimer's disease is likely one of the most significant public health crises of our generation. It is a progressive and ultimately fatal neurologic disorder and is the sixth leading cause of death in the United States, but, unlike the other top ten leading causes of death in our country, for example, heart disease and cancer, it is the one without a way to prevent it or cure it. There is no effective treatment. Yet, at present, Federal funding for Alzheimer's disease research is substantially less than for cancer and cardiovascular research. As a health care provider and a resident of the U.S., this is very concerning to me for the following reasons.

Alzheimer's disease is already a common disorder. Currently, more than five million Americans are living with this incurable disorder. The disease is estimated to—the number is estimated to triple by 2050. In Montana, as you mentioned, Senator, 11 percent of our seniors are living with this disease. Given the slow, insidious nature of the disease, on average, individuals with Alzheimer's survive four to eight years after diagnosis. Some live as long as 20 years. Much of this time is spent with significant mental and physical disability and dependence.

Not surprisingly, Alzheimer's disease takes a significant toll on caregivers and families, physically, emotionally, and financially. Patty Davis described losing her father, President Reagan, to Alzheimer's disease as "the long goodbye." Families and friends say goodbye to an individual slowly over time as the disease gradually steals away his or her memory and other cognitive functioning. In the most severe stage of the disease, nursing home placement is almost inevitable, and I think Kathy has shared that with us.

The financial burden of Alzheimer's disease and other dementias is high at an individual, family, State, and national level. It is the

costliest chronic disease in our society. It is estimated that the national cost of caring for people with Alzheimer's and other dementias will reach $214 billion in 2014, this year. Of those costs, 70 percent of it is absorbed by Medicare and Medicaid. The out-of-pocket spending for individuals with dementia and their families is estimated to be $36 billion this year.

The national annual cost for caring for these individuals is projected to reach $1.2 trillion, with a "T", by 2050. Unless we change the trajectory or course of this disease, the economic burden stands to overwhelm us all. I applaud the steps the Federal Government has taken in recent years to address this, including Congress passing the National Alzheimer's Project Act, which led to the creation of the National Plan to Address Alzheimer's Disease in 2012. The plan is designed to help those with the disease, their families, and caregivers today and work toward changing the trajectory of the disease in the future, but, more is needed if, as a Nation, we want to prevent and effectively treat the disease by 2025.

Now, our efforts in Montana. While working toward changing the course of the disease in the future, we need at a community, State, and national level to deliver better care and support to individuals suffering with this disease and their families and caregivers today. I continue to see the devastating effects of Alzheimer's disease and dementia on my patients and their families. I have watched the health care industry and patient advocacy groups struggle to provide the comprehensive quality care and services these individuals and families require and deserve.

Given the slow progressive nature of the disease with its associated cognitive and physical disability and its associated psycho-social issues—that is the behavioral issues—it will take a village to accomplish this. We need to develop effective dementia-capable systems at the health care organization level and the community and State levels and find new strategies to provide high-quality coordinated care, services, and programs to these individuals and their families and caregivers.

To help achieve this here in Montana, a number of concerned and motivated individuals—Dr. Carlson and Kathy are part of that—have formed the Montana Alzheimer's/Dementia Work Group. This statewide grassroots effort consists of a diverse group of individuals from across the State representing multiple industries or stakeholder groups, including the Alzheimer's Association, the Montana Office on Aging, and other government agencies, patient advocacy groups, caregivers, senior services groups, et cetera.

The Work Group has established itself with identifying the challenges and gaps—has tasked itself with identifying the challenges and gaps Montanans face when dealing with this disease and estimating its economic impact on our State. Using this information, over the next 12 to 18 months, we plan to develop a comprehensive Montana Alzheimer's Disease Plan, similar to what we see from the Alzheimer's Association. This plan will serve as a roadmap specific for Montana to help inform our State government on critical dementia issues. It will also provide a set of recommendations on how to implement and support Alzheimer's disease care and services and will outline what steps our State should take over a given timeframe to achieve key recommendations.

Given the current and future impact of Alzheimer's disease on our State's budget, particularly Medicaid, we feel that developing and implementing a well-formulated State plan now will move Montana toward becoming a dementia-capable State and prepare us for the sweeping economic and social impact Alzheimer's disease will have on us going forward.

To be prepared for the Alzheimer's disease public health crisis, Montanans face the same challenges as other States. Alzheimer's can no longer be the silent or hidden disease. Statewide, we need to increase public awareness about it and encourage early detection and diagnosis. We need to deliver community-based and residential care services in an equitable, cost effective manner. There needs to be better support for family caregivers to help alleviate their burden. Training programs for all caregivers, for example, physicians, nurses, emergency room personnel, with a standardized curriculum needs to be developed to ensure providers have the skills necessary to deliver coordinated, quality dementia care. In partnership with our Federal and State governments and key stakeholders, we need to create dementia-friendly communities that locally provide high-quality coordinated care, services, and programs to individuals with Alzheimer's and their families.'

Montana also faces unique challenges. Given its large land mass and small population, it is not only a rural State, but a frontier State. Rural and frontier communities struggle to recruit and retain primary care providers, who do the lion's share of the work with these individuals. They lack the community-based and residential dementia care services found in larger communities. For decades, one of our State's biggest exports has been its youth. This affects the availability of local family support to help somebody afflicted with the disease. To ensure their care needs are met, many will need to be admitted to a local nursing home, a high-cost place, or leave the community to be closer to family. There is also a shortage of geriatric specialists across the State. Our Work Group and State will need to consider these unique challenges as we develop and implement an Alzheimer's Disease State Plan.

In conclusion, I would like to thank you and the Committee again for the opportunity to testify today and talk about the Montana Alzheimer's/Dementia Work Group initiative. I appreciate your interest and efforts to address Alzheimer's disease going forward. It is clearly a prevalent, costly, devastating condition with high morbidity and mortality. If the course of the disease is not altered, by mid-century, the economic and societal impact of this disease on all of us will be overwhelming. Likely, all of us and our children will be impacted by it.

Working in partnership, we all need to do what is necessary to achieve the goal of the National Plan to Address Alzheimer's Disease, to prevent and effectively treat Alzheimer's disease by 2025. As a physician who provides medical care for these individuals, I look forward to the day when I can offer truly effective preventive treatment options to my patients and family, such as I wish I could for Kathy's mother, and I would like to do going forward for Kathy, for example.

Thank you again for your time on this.

Senator WALSH. Thank you, Dr. Coon.

Again, this is a very difficult disease to deal with, and we are seeing a lot of discussion here, but, again, we want participation from the audience, so if you have questions, please pass them over to your left or right, to the end of the aisle, and my staff will pick them up and we will make sure that we get those questions asked.

Next, we have Dr. Finke. Dr. Finke is a family physician and geriatrician and serves as a national leader in elder care and palliative care for the Indian Health Service. He is the Indian Health Service Representative to the National Advisory Council on Alzheimer's Research, Care, and Services. He now works with Tribes in the Nashville area and nationally in the develop of health care services for elders.

Dr. Finke, please.

STATEMENT OF BRUCE FINKE, M.D., ELDER HEALTH CONSULTANT, INDIAN HEALTH SERVICE, AND REPRESENTATIVE TO THE ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE, AND SERVICES, BILLINGS, MONTANA

Dr. FINKE. Good morning, Senator Walsh. As you said, I am Dr. Bruce Finke, Elder Health Consultant for the Indian Health Service, and I am very pleased to be able to be with you today.

On a personal note, I very much grew up as a caregiver for my beloved grandfather, who had dementia, as well.

In every Tribal community, there are individuals with dementia and caregivers struggling to support them. IHS population health data and workload statistics confirm this, and, the high rates of diabetes, cardiovascular disease, and traumatic brain injury suggest additional population risk for dementia. It is likely that dementia is under-recognized and diagnosed at later stages in Tribal communities, even relative to the low rates of diagnosis in the Nation as a whole.

Clinical care for persons with dementia and support to their families requires significant care management and coordination, resources often beyond the capacity of tribal IHS and urban health programs. Caregiving challenges for families in Indian Country are amplified by the relative lack of formal long-term care services.

Over the years, Tribes have been the lead in the development and provision of these services. The Indian Health Care Improvement Act Reauthorization in 2010 provided IHS and Tribes with new authorities for the services, but so far, these authorities have not received funding, and the capacity of local Tribal and Federal care systems to expand access to long-term services and supports remains a significant challenge.

As others have mentioned, in January 2011, President Obama signed into law the National Alzheimer's Project Act, NAPA, requiring the HHS Secretary to establish the National Alzheimer's Project, including a national plan to overcome Alzheimer's disease and an advisory council to inform that plan. This plan includes a detailed listing of current Federal activities and recommendations for priority actions. The April 2014 plan update describes the progress made to date in the areas of research, care and support, and interagency collaboration.

Through the National Plan, the IHS is working with the Administration for Community Living and the Administration on Aging

around four person-centered goals for improving the care for and the lives of American Indians and Alaska Natives with dementia and their families. These goals are expressed as statements that every individual with dementia should be able to make. I was diagnosed in a timely way. I know what I can do to help myself and who can help me. Those helping to look after me feel well supported, and, my wishes for care are understood and honored.

Our work on these four goals builds on Indian Country strengths: Strong families and a tradition of family caregiving; community-oriented primary care; committed and active public health nursing and community health representatives; and the Tribally operated aging network.

To improve the lives of those with dementia, we are partnering with Tribes and across Federal agencies and bridging the usual boundaries of clinical and community-based services. Some examples: The IHS and Administration for Community Living are working with the VA to adapt and implement the evidence-based REACH VA model of caregiver support, using both public health nursing on the clinical side and the Tribal aging network through the senior centers. The VA is a terrific resource for programmatic expertise in dementia and, importantly, also provides clinical expertise in diagnosis and management of dementia for many of the Native veterans who receive primary care in the IHS and Tribal sites.

Most care for persons with dementia can and should take place in primary care. IHS Tribal and urban clinics are improving access and continuity and enhancing care management coordination for our Improving Patient Care program, a primary care medical home initiative. In recent years, increased funding for purchased and referred care, formerly contract health services, has increased access to the specialty services that support this primary care.

Tribes continue to take the lead in the development and provision of long-term services and supports, and under a Memorandum of Understanding signed in 2011, the IHS, Administration for Community Living, and CMS, the Centers for Medicare and Medicaid Services, regularly coordinate and have developed meetings, webinars, and web-based technical assistance resources to support these Tribal efforts.

Increasing awareness and recognition of dementia in Indian Country starts with access to quality care and meaningful support for individuals with dementia and their caregivers in Indian Country. The IHS is committed to working in partnership with Tribes, Federal agencies, and community organizations to provide individuals with dementia and their families with the best possible care.

Thank you, and I am looking forward to questions and conversation.

Senator WALSH. Thank you, Dr. Finke.

Finally, our last guest was not able to make it today due to weather. It was Mr. Max Richtman, who is the President and CEO of the National Committee to Preserve Social Security and Medicare. He had flight troubles due to weather yesterday coming out of the D.C. area, but, his prepared testimony will also be entered into the record.

The hearing record for this meeting will remain open for five business days for additional statements and post-hearing questions submitted in writing for our witnesses to answer.

This will conclude the official part of our hearing. I am going to now gavel out, and I will move to questions that we have received from the audience.

The first question that we have is from Nita to Dr. Coon. What are State legislators doing to improve financial commitment to assisted living and nursing home placement for seniors?

Dr. COON. It is a very good question, and unfortunately, I do not have an answer to it, because as not being a State legislator, I am not involved in that process. I do not have any answer. I do not know if, Dr. Carlson——

Dr. CARLSON. No, I do not.

Dr. COON. One of the things that we do as we do our—the Work Group moves forward and makes our State plan, it will be vetted and then it will actually be presented to the State legislature, so, if people do have some questions or concerns, or if they also have some potential solutions for what they perceive, it would be great to get it to us so we can incorporate it into our State plan, or they can join us, because we still have an open membership at this point on our State Plan Work Group.

Senator WALSH. Okay. Great.

Next, this question is for anyone on the panel who feels they have an answer. What is being done in other countries, for example, the rate of Alzheimer's in the USA versus China, versus Europe, and does exercise help or other alternative methods help with this disease?

Dr. CARLSON. That is an interesting question, and it is something that I think our Task Force should look into. The cultural differences are immense. Also, an immense difference is single-payer health care, so, the cost—it takes away one concern for a family member, which we hope will change in this country, as well, is am I insured? I do not know. That is a very interesting question. What does France do? Many countries, as was alluded to with Tribal Governments, have a tradition of in-home caregiving, like India and so on. Even some people in India seem to look at dementia as a stage of life and it is caring for the family members, but, it is those caregivers are removed from society just as much there as anywhere else, so, the incidence in the U.S., I do not believe, is any greater, other than the increase in incidence of diabetes, which is a risk factor.

Senator WALSH. Dr. Finke.

Dr. FINKE. I would just comment that the National Alzheimer's Project Act requires, among other things, that HHS look—or, coordinate with international bodies to fight Alzheimer's globally, and there is a significant effort through that work to coordinate with other nations. On the research side, through the National Institutes of Aging, there is quite a bit of activity to develop—and the Alzheimer's Association actually is a part of that work—to develop a common basis for research efforts and a sharing of information across national boundaries to facilitate research.

There has also been quite a bit of sharing. There was a G–7, G–8 meeting in London over the past couple of years—I am not sure

of the exact date—at which nations shared their approach to addressing Alzheimer's.

The language that we have—that the Administration for Community Living and the Indian Health Service adopted around patient-centered goals, in part, comes from language that Great Britain has adopted as a way of framing their efforts to improve care for persons with Alzheimer's.

Dr. COON. I have an answer more on a clinical level than—I think it is a great idea for us to look at what other countries are doing, in particular, England is doing with regards to this disease. I know that as a health care provider, I often go to their NICE site, which is the National Institute for Clinical Excellence, and they are much more robust in the information they provide than we get anywhere else in this country, and I think that does need to be something that needs to be addressed.

I want to answer the second question, because I think there was something about exercise. You know, we do not have any effective treatments. I do want to say, I am one of probably the few people that keep referring to it as a chronic disease. We do know there are three phases, pre-clinical into mild cognitive impairment, and, when people start having problems with mental functioning, we actually call it Alzheimer's disease, but, it is a continuous disorder, similar to what we see for heart disease. Plaque gets laid down. You finally have your heart attack. This means plaque and tangles get laid down and you finally get the disease.

Anywhere along that spectrum, we encourage exercise. We want to control other risk factors, such as diabetes, hypertension, elevated cholesterol, work and do those vascular risk factors so that that is not a double-whammy to the brain, leading to cognitive impairment, so, I think, exercise is very important.

Also, what I often counsel my patients to do is mental gymnastics, and that there are actually three apps available for Smartphones. There are also programs available that have people go through, and set up by neuropsychologists and neurologists have set up these programs that allow people to really work on the different domains, whether it is memory, visual-spatial, or other areas of the brain that are affected by this disease, for them to try to improve it. I know that there has been some thought that these programs may actually help with working memory in people who have mild cognitive impairment.

Mental gymnastics, physical gymnastics, and controlling vascular risk factors are very important, which means lifestyle change, which, I think, we hear all the time from our doctors, but all of that is very important, so, I hope that answered that question that the person was asking.

Senator WALSH. Any other input on that question?

Okay. This next question is from Lisa, and it is, again, to the panel. What do we believe can be done to help caregivers?

Ms. BURKE. Well, I think we need two things, as a caregiver. One, a sense of humor, and I do not think that should be underestimated, and patience, and, we need education, as I stated before, so many times, the diagnosis comes, and it is kind of like when people hear the word "cancer." It is like it is a shock and you do not know what to do, where to go for help, and, there are all kinds of re-

sources, whether they be local ones, whether they be websites, but, I think education is primary, not only for the person who has been diagnosed, but for their caregivers and for the community as a whole, as I mentioned before, because there is a lot of misunderstanding.

We have—fortunate, in a big city like this, we have different caregiver groups. I mean, there are ones through the Billings Clinic, ones through the Alliance, ones through different nursing homes, and they provide speakers and sharing of experiences, like I mentioned, so that caregivers are maybe not surprised by the progress or certain situations that come past because they know that other people have had them and potential ways to help work with them.

Senator WALSH. Dr. Finke. I am sorry. Go ahead, Dr. Coon, first.

Dr. COON. You know, I think that there are probably several things that we need to do for caregivers. One is education, but not only for the caregivers, especially when they are dealing with individuals with the significant behavioral issues we see with this disease, but we need to have better education of health care providers that are working with these individuals, nursing home staff, assisted living staff, so that, together, they can really address the situation that—the behavioral issues and the problems we see taking care of this individual.

I think we need to do a better job of coordinating care. I think there is a woman in the audience, now, and she is part of our group, as well, and I always remember, her husband was diagnosed with the disease. She would walk out of the provider's office and say, what do I do now? I often refer to it as opening Pandora's box, and, there was not the coordinated care she needed for her to figure out how do you go along and make sure that she manages the disease successfully. She actually stumbled around for several months before she went to the Alzheimer's Association.

Finally, I think that we need to monitor the caregivers' health. We need to make sure that we provide them respite and resources for that, because it takes a heavy toll on them physically and mentally. We need to monitor them for depression, and, we need to relieve some of the financial burden on the family, as well.

Senator WALSH. Dr. Finke.

Dr. FINKE. I will answer that, that there is a small but important body that is around specific interventions that improve caregiver health. Some of this work comes out of the REACH research from the—funded by the National Institutes of Aging. REACH stands for Resources for Enhancing Alzheimer's Caregiver Health, and, this work demonstrated an intervention that actually did improve outcomes for both caregivers and persons with dementia. The VA has taken that work, adapted it for the VA, evaluated it, and is now spreading it across the system as the REACH VA program, a highly successful program within the VA.

As I mentioned briefly earlier, the IHS is working with the Administration on Aging within the Administration for Community Living with the VA to take that model and bring it into Indian County. I think there has also been work through the Administration on Aging outside of Indian Country to adapt that model, but that is—I think we are really excited about this as a structured

way to support caregivers as part of the caregiver—as part of caring for the individual with dementia.

Dr. CARLSON. One thing, I think, that cannot be overemphasized is the importance of diagnosis, early diagnosis as soon as practical, allowing the patient to plan and the caregivers, before they actually are caregivers, to know what resources are available. That is what we are trying to implement with Benefis Health System.

A telling study was done by Riley McCarten in Minneapolis. He took 8,000 veterans 70 years of age and older who had no record of any cognitive impairment in their records. They were seeing the physicians for other reasons. He implemented, or tested each one of these, and with a very simple cognitive test—it takes two or three minutes—27 percent of those failed, and on followup, 95 percent of those who failed were shown to have clinical dementia, so, if those people were identified earlier on, there would be less people not bringing their parents or their wife or husband in a moment of crisis, but having time to find the resources and to get help when they most need it.

Senator WALSH. Dr. Carlson, are these tests available from your local physician, or how would you——

Dr. CARLSON. What we are trying to do now with Benefis, and this has been implemented in Minneapolis, is the test is actually—it is called a mini-cog. You are just asked to remember three words over a, it is, like, a two-or three-minute period and draw a clock with a particular time on it, so, it would be like the vital sign. When the nurse takes your temperature and height and weight and your blood pressure, they would administer this simple test before you go and see the physician, and then the physician would be the one responsible to followup, if necessary.

Senator WALSH. Okay. Great. Thank you.

The next question is from Janice. It is for Dr. Carlson. Has the McLaughlin Institute applied for funding from the National Active and Retired Federal Employees through the National Alzheimer's Association? And, then, where else have you applied for and received funding?

Dr. CARLSON. The bulk of our funding has come from the National Institutes of Health, and I was not aware of this funding source, so thank you very much, if funding is available through that, but, most of it is through the Federal Government, both National Institute on Aging and National Institute for Neurologic Disorders and Stroke. We also have applied for—the Alzheimer's Association gives grants, as well.

One thing I would like to emphasize is the success rate now is terrible. As recently as seven or eight years ago—the way the grant applications work at the National Institutes of Health is it goes to a panel of scientists for peer review. The applications are ranked and given a percentile score, so, it has always been competitive, which is a good thing, but they would fund between 15 and 20 percent of these basic research applications. The top 15 or 20 percent were very likely to receive funding.

With the National Institute of Aging now, the cutoff has been as low as six or seven percent, and I do not think the peer review system has the resolution to tell—to say that an application that scores in the top six percent is significantly different from that

which scores in the top ten percent or fifteen percent, and that is where increased funding could really make a difference, in getting realistic—going back to a realistic competition rather than this hyper-competitive situation we are in now.

Senator WALSH. What country would you say has taken the lead role on research, as far as investment and moving forward?

Dr. CARLSON. Well, as a percent of GDP, places like Israel, Great Britain, but, still, and this is why it is worrying, the U.S. still has the best research in the world, but, other countries, the rate of increase in China and India is frightening, but, we are still—you know, with our university system and our funding for the National Institutes of Health, even though it is going down, we are still at the top, but, it is not a God-given right to be at the top and I think we have to work on it and have increased funding for research.

Senator WALSH. Okay. Ms. Burke, this question is for you. What would your advice be for someone who has recently been diagnosed with Alzheimer's as their first stop to find information or support services, especially for someone from a rural part of our State?

Ms. BURKE. I think the Alzheimer's Association. We have a fantastic Montana branch. We also have a national one. The glitch that we have discovered in our Work Group is that access to information is difficult in our rural area. They have fantastic websites, but if the Internet is not working well, that is a problem, but, I think, they could contact the office here in Billings. There are also additional websites, and, like I said, I wrote down some of the ones that I have used, and the government now has one, Alzheimers.gov.

I think the education is important. If we can help each other figure that out via the website, you can take that information and talk to your local care provider. You could probably make arrangements to make a long trip to Billings, depending on where you live in the State, to come here, but, education is so important, and the support of people who have been dedicating their organizations and lives to this disease to help for education is something that needs to be tapped into.

Sometimes, knowing about resources is a difficult thing, and I think the Alliance does a really good job of that. They have a book called, Whom Do I Ask?, and it is not just about Alzheimer's, but it is all kinds of resources that are available in the Billings community. Again, that might not be as helpful for the geographically isolated parts in our State, but it is a place to start, because they are always willing to share the knowledge, and that is what needs to be done, in my mind.

Senator WALSH. Okay, great. This question is from Marcia and it is for me, and the question is, what will the Ryan budget do to Alzheimer's?

My answer there is that the House passed Congressman Ryan's budget in April. It does not specifically cut Alzheimer's research at the National Institutes of Health, but it proposes an almost $800 billion to be cut over the next decade from the non-defense/discretionary budget, so, realistically, that would cut NIH funding by as much as one-third by 2024, so, that is something I am not supportive of. I think that, you know, based on what we have heard

here today, we need to continue to invest and put additional resources into research.

With the McLaughlin Institute, and when I was serving as the Lieutenant Governor, along with Governor Bullock, we visited the McLaughlin Institute to see what they were doing, and we looked at it like the—you know, not only from the United States perspective, but Montana, having this resource right here in the State of Montana, we could become a leader in the United States with the resource that we have right here in our backyard in Great Falls, Montana.

I know that—and, that is one of the reasons Governor Bullock initially invested in, or put some money into research. I am confident that he will continue to invest in this area, because with Montana's—you know, our population is aging and we need to invest in this area, but not only from the State of Montana, but we could become a leader nationwide where other States are coming to Montana to find out what we can do—what they can do to better prepare for this terrible disease.

The next question, again, is from Elaine for Dr. Carlson. Please discuss family DNA and Alzheimer's. I am sorry. That one, we already had.

This is the next question. Again, it is for me. What can be done to invest in research, and how can we prioritize help for families?

My answer is that there is clearly more that we can do. I think we have heard from all of our panelists that education is very important. Early identification is important, and, communication is extremely important, but, two things that we can do. You know, there are two bills that we should pass immediately. The first one is the Alzheimer's Accountability Act, which would require an annual budget for the NIH for Alzheimer's research to meet the goal of preventing and treating Alzheimer's by 2025, and, then, we should also pass the HOPE Act, which will open more Medicare services for Alzheimer's treatment, so, those are two things that I think that we can do immediately to take on—to take steps forward.

This next question is for Dr. Carlson. Again, Dr. Carlson, I want to thank you for the great work that you do at the McLaughlin Institute. Your testimony did a great job of showing that Federal funding for Alzheimer's research may not be enough, given the tremendous challenges that this disease presents for our country, but, the question is, what are some of the opportunities for further scientific research that are not being taken advantage of now, but would be taken if Congress increased investment in Alzheimer's research?

Dr. CARLSON. That is a very good question, and what happens when the funding gets tight—this is not unique to the National Institutes of Health, but just in general, if there is a limited amount of funds, people become more conservative in distributing those funds, so, the more innovative ideas are the ones that suffer, so, the grants that are funded are ones that are on paths that seem to be promising, even though those paths have not proven to be successful, so, someone who proposes something entirely new and entirely different and does not have preliminary results to support it, they are not going to get funding.

Basically, it is trying to identify the more innovative, new approaches to research that have not been tried before, and if there is enough money, you can fund those things rather than the same stuff that has yielded good results, but it has not yielded any preventative treatments or cures just yet.

Senator WALSH. Okay. Thank you.

Finally, the last question that I have is for Dr. Coon. You know, we are looking forward to seeing the ultimate work of the Montana Alzheimer's/Dementia Work Group. Please do not hesitate to reach out to my office if there is anything we can do to help. We want to be helpful. Although you still have work to do, what are your initial thoughts about unique approaches that would be particularly effective in a rural State like Montana?

Dr. COON. You know, I think that what—as we, as a Work Group, speak, what we really are talking about, how do we improve coordinated care within not only the State, but in the community, in general, so, it is really looking at community efforts to coordinate care, bring like resources available to those individuals in the community, and that is, I think, the main challenge we are going to have.

There are models of care out there that currently could be implemented, but we are talking about a community at a State level. Some of that—and I am going to make a plea for another research bucket—so, there also needs to be dollars put toward health services research that allows us to take these models, implement them in communities to see if we can improve the outcomes of these individuals by truly providing coordinated services throughout those facilities. Higher education, better education with these individuals, having those resources available to the families, that all needs to take place at a community level and not necessarily at a State, at a Federal level, so, I think, that is the direction where we are really going for the Work Group at this time.

Senator WALSH. Okay, great.

I do have one more question, and that is for Dr. Finke. Again, I want to thank you for coming to Montana to share your experience. Alzheimer's is a disease that affects everyone, no matter who you are or where you live. Can you go into a little further detail about the Indian Health Service outreach to Reservations about Alzheimer's, and what should Montana Tribes expect to see from IHS in the coming years?

Dr. FINKE. Thank you. The Indian Health Service is a primary care-based health system, as you know, and so our work around the Alzheimer's and dementia on the clinical basis really is going to be about building the structures and the platform of care in the primary care level to be able to provide the kind of coordinated managed care that individuals with Alzheimer's and their families need.

I mentioned in my initial comments the Improving Patient Care Program, which is the medical home model, and I think what we see out of the medical home model is a more robust platform of primary care. We see this already at Northern Cheyenne, for example, where they have been working on this model longer than others and they have begun—they have care teams building continuity of care with panels of patients, and those teams are actually doing

outreach and care management for elders, for frail elders and elders with dementia, out of their care teams, and, I think, building a more robust, capable platform of primary care will help us to manage—support and manage care for folks with Alzheimer's and their families.

I also think we should expect to see, as we work with the VA, with the Administration on Aging around the REACH intervention, more structured support for family caregivers and, really, an approach that says, care for a person with Alzheimer's involves care for those who care for them, as well.

Senator WALSH. Okay, thank you.

Just a real quick survey. Just a show of hands of how many in our audience today have been impacted in one way or another by Alzheimer's.

[Show of hands.] Wow. When you look at just our audience here today and our State, sooner or later, we probably will all, in some way or another, be affected, so, whatever we can do to provide additional resources for research to combat this problem, it is something that we should do, and, I can promise you that I will work very hard in the U.S. Senate for the time that I will be there to fight for additional resources, because this is a very debilitating disease that affects so many of us in the State of Montana and around the country.

Again, I want to thank all of the panelists who came today with your testimony. We will make sure that—as a member of the Aging Committee, I will take this information back to Washington, D.C., and share it with my colleagues on the Aging Committee, so, thank you very much for being here.

I want to thank all of the—everybody who attended today for showing up just because of your interest in this. I am confident that we will move forward and progress in fighting this terrible disease.

Then, finally, I would like to—you know, when we put committee hearings and meetings like this together, I get to sit up here in front and take a lot of the credit for doing this, but I can tell you that it does not happen without a lot of work from a lot of people behind the scenes, and, especially, I would like to have Jim Corson and Matt Peterson to please stand up and take a round of applause.

These gentlemen are members of my staff here in Billings and they do a tremendous amount of work, and so if there are other issues or input that you want to have for our staff that you want us to receive in Washington, D.C., please do not hesitate to reach out to them.

Again, thank all of you for being here. I think that we have some refreshments and cookies in the back, and, again, thank you so much to our host facility—yes.

Ms. GIBSON. Senator, I am Heidi Gibson from the Alzheimer's Association, the Montana Chapter. I would just like to cordially invite you to the Walk to End Alzheimer's in Billings September 21st at the zoo. There is information on the back table, not only about the walk, but just about connections, caregiving, and we are really better together, but also bills that the Senator mentioned, the HOPE Act and also the Alzheimer's Accountability Act.

Senator WALSH. Thank you, Heidi.

Any other comments?

[No response.] Okay. Again, thank you all, and enjoy the rest of your day.

[Whereupon, at 11:06 a.m., the Committee was adjourned.]

APPENDIX

Prepared Witness Statements

Testimony of Kathleen Burke
Senate Special Committee on Aging Hearing
Alzheimer's disease: A Big Sky Approach to a National Challenge
South Park Senior center, Billings, MT
August 13, 2014

Senator Walsh, individuals who recommended my participation, fellow panelists, and audience members, thank you for participation in this vital hearing. It was with a humbling sense of responsibility that I accepted the invitation to testify and bring a common face to Alzheimer's. According to the 2014 Alzheimer's disease Facts and Figures report by the Alzheimer's Association, most of the general difficulties that I will present are experienced by many Alzheimer's families, with slight variations. I apologize ahead of time for speed reading a subset of my submitted testimony, but I am concerned about the time don't want to miss points, especially educational ones.

My name is Kathleen Burke and unfortunately I have a family history of Alzheimer's and related brain disorders on both sides of my family for at least two generations, including grandparents, both parents, aunts, and uncles. I helped my maternal grandparents in the 1970s when I was the only relative within 900 miles. I resumed caregiving when my mother Shirley was diagnosed with Alzheimer's in 2002 and my father Jack in 2010. My almost 92 year old mother, entered a nursing home in January 2013 initially for rehabilitation from mild strokes, but stayed permanently due to her Alzheimer's, which is now in the end stages. My father, who was on medication for his mild symptoms of Alzheimer's, died last September of pancreatic cancer at the age of 88.

I am honored to speak on behalf of the estimated 48,000 caregivers for the 18,000 Montanans currently diagnosed with Alzheimer's disease. Partially due to Montanans' longer life expectancy, the number of Alzheimer's patients is projected to increase in Montana by 50% by 2025. This is a startling forecast that we need to derail. When the government provides to Alzheimer's disease the level of financial support that has been given to cancer and heart disease research for the last 40 years, tremendous strides should also be accomplished for Alzheimer's.

The Alzheimer's Association provides this list of ten warning signs to assist in deciding if one should seek medical consultation regarding actions exhibited by individuals. The signs are memory loss that disrupts daily life; challenges in planning or solving problems; difficulty completing familiar tasks at home, at work, or at leisure; confusion with time or place; trouble understanding visual images and spatial relationships; new problems with words in speaking or writing; misplacing things and losing the ability to retrace steps; decreased or poor judgment; withdrawal from work or social activities; and changes in mood and personality. According to their 2014 Alzheimer's Disease Facts and Figures report, the personal difficulties that I will present are experienced by many Alzheimer's families, with slight variations.

I was excited and relieved when my parents began receiving Veterans Administration (VA) funded care through the Yellowstone County Program of All-inclusive Care for the Elderly (PACE) thinking that their health care needs were finally arranged for life. Unfortunately Montana decided to be the only state to withdraw its participation after providing partner funding for only two years. Since PACE closed in 2011 the money that VA was providing for my parents participation was not available for other VA programs. I have arranged care using the VA, Medicare, private supplemental medical insurance, medical personnel, day care, in-home care, family, and other sources. I worked to arrange the first day care Provider Agreement for VA in Montana, but it failed. We have experienced waits of up to a year for

determination of eligibility for benefits. I have more forms to submit for benefits, but it is depressing just thinking about the process. My father's 100 % service-connected disability benefits included free dental, free drugs, and VA contracted nursing home, but not my mother, who is actually in more need now, does not get these benefits,. Dad died the day before he would have taken advantage of the free nursing home benefit. The VA does not work well with Medicare, so it would really help our family if benefits could be applied to either family member when both are veterans and one did not get to receive these benefits.

Personality changes are common and can cause rifts in families if one does not remember that the disease adversely affects the person we used to know and relationships with them. When my father was yelling at me, I got very close to his face because he was hard of hearing and asked him loudly, "Do you know how hard it is to help you as much as I do when you yell at me like this?" He responded, "That's just the way I am and I'm too old to change."

Memory loss is a classic symptom. Mom put an appointment on the calendar, but didn't know why. I took off work and met the cemetery salesman. He was discussing plots in a veteran's section of a local cemetery, so my parents thought it was free for vets. I was relieved recognized the salesman, mentioned Mom's Alzheimer's, and explained they would not be buying.

Another sales person sold Mom a medical insurance policy that she thought was part of Dad's employer's coverage, which it wasn't. My parents had unneeded double insurance with five years of payments, which neither of them understood until I discovered it while trying to fix their checkbook.

One of the typical warning signs was when my parent's check book was mismanaged by Mom, who took care of the family finances. Thinking it was advertising, Dad would discard mail without opening it. Mom had accepted a free Reader's Digest Condensed book. If you did not tell them to stop, they kept sending them for a charge. I found a $52 bill that started out at $19 and all the rest was interest charged when she forgot to pay and Dad didn't realize it was overdue. I explained the dementia situation and paid the original bill.

Another typical warning sign was when Mom couldn't complete familiar tasks, such as cooking. Mom was baking a frozen pizza for supper, with the plastic wrap still on it. I came into the house to the smell of smoke. She said she always did it that way. Needless to say, it was no longer safe for her to cook and Dad didn't know how, so that required additional food preparation problem solving on my part.

Confabulation can be exhibited by Alzheimer's patients as misinterpreted memories. My mother told the nurse that her sister had committed suicide, when it was actually the daughter of her bridge partner.

Anger and anxiety are experienced by many Alzheimer's patients. Once at work I had to interrupt a class to deliver a message to a student about his family in Great Falls. His Alzheimer's afflicted father had beaten his mother so severely that she was taken to the hospital and his father was arrested.

Loss of problem solving skills and poor judgment are exhibited in different ways. Mom was scheduled to have thumb surgery for arthritis, but she decided to cancel it because she was dominantly right-handed. For several weeks before the surgery we practiced using her left hand for eating, tooth brushing, toileting, and other personal needs. It took much patience and practice, but she finally had the surgery, which greatly reduced her arthritic hand pain.

Mom was dropped off at a casino to play cards, but Dad remembered the wrong day so no players were there. Rather than thinking to phone family members, she accepted a ride from a stranger to take her home. I was shocked because this could have turned out very poorly had he taken advantage of her.

Dad drove Mom to the Senior Center for cards. He was confused, thought I was going to bring her home after work, and phoned when we did not show up by 5:30 PM. When I got to the center, which closed at 5 pm, she was sitting outside waiting for pickup.

My parents' medical insurance premiums were supposed to be paid for life by Dad's large retail employer, but they have had to pay them for approximately 10 years. A promised $100,000 life insurance policy was cut several years ago to $8,500. I realized after his death that he was offered some type of life insurance that he could have purchased through the employer at a reduced rate, but he was so angry he refused it without discussing it with his family.

Many Activities of Daily Living (ADLs) need to be assisted by caregivers. I would call Mom daily to ask if she had taken the pills set up for her and if she was dressed. I started to find chewed gelatin pills in the garbage and on the floor. One day she had two shoes of different colors, whereas another time she had on two right loafers. One night when I saw her limping and asked why, she didn't know. I took off her shoe and found a sock crammed in the toe of the shoe. Dad hadn't noticed when he had put on her loafers that day. He was angry when I suggested he had to pay more attention when helping before day care. His typical response was, "You don't understand."

When my Dad had a brain abscess in 2007, I had to take Mom to work with me because I could not safely leave her by herself. It was difficult to find senior day care in Billings then, it is still limited, and may require a contract as opposed to meeting drop-in needs. The client has to be quite independent to participate. As her disease progressed, I was given a week to make toileting arrangements or she could no longer go there. I found a certified agency who had a person that the VA paid to help her for 30 minutes each day Monday through Friday.

It is theorized that social isolation and lack of physical and mental exercise might be risk factors for Alzheimer's. Mom did not drive, so she was always dependent on others for transportation. Since diagnosis most of her day was spent being a meticulous homemaker, knitting afghans, and playing solitaire. Outings were to buy groceries, go to church, play cards, and to eat out. She really looked forward to playing cards about four times a month with various groups. Over several months all phoned me to say she couldn't play with them anymore because of forgetting to pay her dues or for food ordered or inappropriately announcing what cards she had when they were good. As a family we would try to do some daily brain activities, such as card games, Wheel of Fortune, or the monthly Readers Digest vocabulary test. Dad would also do search-a-word puzzles. Mom could not do the special 60th Anniversary search-a-word I made for them in 2005, saying the letters were too small for her to read. She didn't realize her mental contribution to difficulties.

It is common to exhibit increased confusion in unfamiliar surroundings. During an Emergency Room (ER) trip, I explained to the doctor who I was and about Mom's dementia, but he did not want me to answer questions for her. He asked Mom who I was. She looked at me, hesitated, and said, "She is a very good friend." She gave no name. At that point the physician accepted my answers. On another occasion I had to move my car when Mom was in the hospital. She was very confused, so I stopped at the nurses' station to remind them to watch her while I was gone so that she did not remove the IV or pull off the chest leads for the 24 hour 12 lead ECG. When I returned after less than 10 minutes, no one was with

her and she was bleeding from where she had pulled out the IV and had several of the leads removed. On December 23 I had to stay in the chair next to her bed all night to prevent her from interfering with overnight testing when the hospital was unable to provide the care they promised. I went directly from the hospital to my regular eight hour job. When Mom moved into the nursing home, I was concerned with her walking in unfamiliar surroundings. I was not happy that the bed had no safety railings, but rather a low level plus a pad on the floor on which to land if she fell out of bed. The second night the wheels on the bed were not locked, she fell out of bed onto the hard floor between the bed and the wall where there was no pad, suffering a cut on her arm. She could not get up and staff did not find her for approximately two hours. Mom's increased confusion in unfamiliar surroundings, coupled with lack of Alzheimer's knowledge on the part of physicians and nurses, made for miscommunication and injury. These instances point out that Alzheimer's education is needed for everyone, including medical personnel, to meet the needs of these patients. Employers are another group for which education would improve understanding as to why employees need to be gone from work for caregiving for family members with Alzheimer's.

Several years ago when I came into the house, mom was not sitting in her chair next to my dad. He said, "We lost your mother." I was shocked, thinking she had died. He then continued, "I never thought this could happen to such a smart person. The sparkle is out of her eyes. She'll never again be the same."

Even after physical therapy instruction Mom could not get up by herself after she had fallen and Dad could not get her up by himself, so he would have to call my brother or me to come help. Dad was afraid to go outside to water the flowers for fear Mom would fall inside and he would not hear her.

My brother was fearful that my dad's wanting to save money by keeping mom out of a nursing would take a toll on Dad's failing health, which happens to caregivers. When I was forgetting things at work, I underwent testing and was told my memory problems were related to work and caregiver stress. I now have baseline data that can be referred to in the future.

I have utilized the redirect technique for both parents. I explained to Dad how important it was to have two people at medical appointments, but he looked on it as an infringement on his independence and privacy. He would stand in the parking lot, or worse, in the reception area in the doctor's office and yell at me, saying I did not need to be there. I knew his social filter was affected by his disease, but I still found this quite embarrassing. I believe a sense of humor helps cope with this disease, so our family teases a lot. I told him that since he was so hard of hearing and didn't understand medical terminology I would serve as his personal secretary. With his retail management background, he was used to having people do things for him, so he could relate to this. Finally, although reluctantly, he allowed me to help and would actually introduce me as his personal secretary.

Driving is a huge issue for Alzheimer's victims and their families. After 12 years of discussion in caregiver meetings, I can remember only three people who gave up driving on their own, which was not the case for my dad. This problem warrants a separate discussion at a different time.

At the end of their 68th anniversary celebration in the nursing home on July 4, 2013, Mom pushed Dad away when he bent over to kiss her good bye, saying that her husband would not like that. It was difficult for me to see, but probably worse for him since he would not talk about it. He was diagnosed with pancreatic cancer in August and didn't visit her after that. Knowing that she would not understand, it still hurt not to tell her that her husband died of pancreatic cancer or that his funeral was one day

before her 91st birthday. This was a stressful time for all family members, who had to change from being sad to happy in a 24 hour period to celebrate her birthday.

I considered retiring early so I could take care of Mom, but realized it was a 24/7 job for which I did not have enough support. I still feel guilt, even though I know it was a logical decision. I visit her daily, but she usually does not realize who I am. Her disease doesn't allow her to speak many words, she is confined to a wheelchair, and her hands are contracting. I miss both of my parents; one who died physically and one who has died mentally.

My faith has helped me cope with this disease. I think God has a sense of humor, realizes that patience is not one of my better virtues, and has provided multitudinous Alzheimer's opportunities for me to work on that virtue.

In closing, thank you for allowing me to testify. With proper funding, I am looking forward to what can be done for Alzheimer's to prevent the terrible Montana forecast from becoming a reality.

George Carlson, Ph.D., Director & Professor, McLaughlin Research Institute,
Great Falls, Montana

Testimony as a witness before the Senate Special Committee on Aging Hearing
Alzheimer's Disease: A Big Sky Approach to a National Challenge
August 14, 2014
South Park Senior Center
Billings, Montana

Thank you Mr. Chairman and members of the Committee for providing me the opportunity to testify today on behalf of McLaughlin Research and the people in Montana who are or will be afflicted by Alzheimer's Disease or related dementing illnesses. MRI is an independent, non-profit research organization in Great Falls, Montana where we conduct basic biomedical research to understand, and ultimately prevent, neurodegenerative diseases like Alzheimer's, Parkinson's, and related disorders. I thank Senator Walsh and members of the Special Committee on Aging for recognizing the looming national crisis that will be caused by Alzheimer's disease and other dementias as our population ages.

The personal tragedy of dementia, the loss of identity and memory, cannot be fully comprehended by those whose family members have been spared. The suffering caused by Alzheimer's and other degenerative brain diseases of later life is reason enough to expand our efforts to find a way to prevent this illness. Unfortunately, the economic impact of dementing diseases also is immense. Currently, according to the Alzheimer's Association, 5 million Americans (~25,000 Montanans) are currently afflicted with Alzheimer's or related dementias with an annual financial cost approaching 100 billion dollars. By 2050, if nothing changes, as many as 16 million Americans could be affected, costing the economy 1.2 trillion dollars. However, investment in research can bend this cost curve.

The effectiveness of biomedical research, funded largely by the National Institutes of Health, is unquestioned. Progress against cancer and heart disease over the past 50 years, to name only two examples, has been remarkable with effective therapies that can prevent disease, prolong survival, and effect cures. For example, the impact of statins on lowering risk of coronary artery disease and heart attacks is well known. In contrast, Alzheimer's disease was identified as a distinct clinical entity over 100 years ago and there are still no therapies capable of even slowing the inexorable course of neurodegeneration. It is telling that for every $28,000 the federal government spends on caring for patients with Alzheimer's disease and related dementias, only $100 in federal funds goes to support research on these disorders. Funding data from the National Institutes of Health shows that funding for Alzheimer's disease in 2013 was approximately $412 million, in comparison to $3 billion for AIDS research, $2 billion for cardiovascular disease, and $5 billion for cancer research. Support for research into all diseases is important and results

often shed light on apparently unrelated disorders, but the financial impacts of dementia on society is now greater than those of either heart disease or cancer.

On the positive side, the Obama administration has developed and is implementing a National Plan to Address Alzheimer's Disease. Unfortunately, funding is below the levels needed to accelerate progress towards the worthy goals of developing treatments that would prevent, halt, or reverse the course of Alzheimer's disease and of improving early diagnosis and coordination of its care and treatment. Sequestration has further eroded the support available for research.

New approaches developed using mice by MRI scientists and our collaborators are being used to identify the earliest molecular changes in neurodegenerative diseases with the goal of finding markers in the blood that can indicate the presence of disease processes decades before clinical signs or symptoms appear. Although there is no treatment now, future therapeutic interventions are much more likely to be successful in the early stages of disease. We are also beginning to understand the mechanisms for the prion-like spread of Alzheimer's disease pathology within the brain, potentially offering new ways to intervene in the disease process. Recent advances show that the way disease spreads from one region of the brain to another is similar for Alzheimer's, Parkinson's, Amyotrophic Lateral Sclerosis (Lou Gehrig's disease), and frontotemporal dementia, as well as chronic traumatic encephalopathy, which arises from traumatic brain injury in athletes and our troops returning from Iraq and Afghanistan. We understand more about Alzheimer's and other dementing disease than ever and research is at a pivotal point—it is largely a matter of our elected representatives deciding that a cure is worth funding. At the same time that science is close to making a difference for people who will suffer dementing diseases, federal funding for medical research is drying up. The American people know that our nation's best weapon against disease and spiraling health care costs is biomedical research.

We at McLaughlin have started an exciting new initiative to speed up the translation of basic research findings into medical practice. To make a difference for current and future patients with dementing illness, MRI is collaborating with Benefis Health System in Great Falls to develop a Center for Aging Research & Memory Care—a unique partnership between an excellent community hospital and an internationally recognized research institution. This "center without walls" is not a place but an exciting new initiative aimed at improving patient care now and at developing new avenues to search for ways to prevent disease. As only one example, we will transplant stem cells from Alzheimer's patients into mice to watch the progression of disease in a living brain, providing a new tool to test potential therapies and giving us real hope for a cure. With Federal support shrinking, the State of Montana stepped up with a grant of nearly $1 million in 2014 as seed money for the Montana Center for Aging Research & Memory Care. Thank you Senator Walsh for your support of this appropriation when you were Lieutenant Governor.

Americans also recognize that our nation's global leadership in science is tenuous.

Our leadership position will evaporate if policymakers shortchange government support for the basic research that is essential for finding cures for disease and for fueling innovation in the private sector. Unlike the U.S., countries like China and India are rapidly increasing their investments in science. MRI scientists are receiving funding from India's National Center for Biological Sciences to help establish a mouse genetics facility and a cardiomyopathy lab at Bangalore's Institute for Stem Cell Biology and Regenerative Medicine. While this international collaboration is exciting, it points out the appreciation that other countries have developed for the importance of basic research. Before this, I had never imagined that our research in Montana would be supported by funds from a developing country.

To maintain America's leadership in biomedical research, as well a find ways to prevent dementia and other devastating diseases, it is essential that talented young people pursue scientific careers. We at MRI have observed first hand decisions by talented postdoctoral trainees, discouraged by the downturn in grant application success rates, to abandon basic research for careers that offer more security. Support from NIH is essential to foster and retain the next generation of research innovators. Innovative research cannot be turned on and off like a spigot; it only yields results over time and with consistent effort. If Congress and the Administration let funding for Alzheimer's and related disorders stagnate as inflation further eats away at its value, it will compromise progress at a time our health care system and the nation can least afford it. Discoveries made at MRI and research organizations across the country have set us on the road to finding a way to prevent or cure dementing illness; it is essential to find a way to enhance federal support for Alzheimer's disease research. Thank you Senator Walsh and members of the Special Committee on Aging for this opportunity to testify on behalf of the research community and, more importantly, families affected by dementing illness.

Senate Special Committee on Aging
Alzheimer's Disease: A Big Sky Approach to a National Challenge

Statement of Patricia Jay Coon, MD
Billings Clinic, Billings, Montana
Co-chair of the Montana Alzheimer's/Dementia Work Group
August 13, 2014

Good morning Chairman Walsh and distinguished members of the Senate Special Committee on Aging. I am Patricia Jay Coon, MD, a physician who has practiced geriatric medicine for nearly thirty years, the majority at the Billings Clinic in the frontier state of Montana. I also serve as co-chair of the Montana Alzheimer's/Dementia Work Group. A state-wide work group established this year with the goal of improving the lives of individuals in Montana with Alzheimer's disease and other dementias and to provide better support for their families and caregivers. It is an honor to be here today to discuss our efforts and the challenges we face caring for individuals with this devastating disease.

Framing the Dialog: The Alzheimer 's Disease Epidemic

Alzheimer's disease is likely one of the most significant public health crisis of our generation. It is a progressive and ultimately fatal neurologic disorder and is the sixth leading cause of death in the United States. It is the second most feared disease, second to cancer. But unlike the other top 10 leading causes of death in our country, e.g., heart disease, cancer, diabetes, Alzheimer's disease is the only one without a way to prevent or cure it. There are no effective treatments at this time. Yet, at present, federal funding for Alzheimer's disease research is substantially less that that for cancer and cardiovascular research. As a health care provider and a resident of the U.S, this is very concerning to me for the following reasons.

Alzheimer's disease is already a common medical condition but the number of Americans with the disease is rapidly growing. Currently more than 5 million Americans are living with this incurable condition. This number is estimated to triple by 2050. In Montana, 11% of our seniors live with the disease and by 2025 the number of individuals is expected to grow by 50%. Given the slow, insidious nature of this disease, on average individuals with Alzheimer's survive four to eight years after diagnosis; but some live as long as 20 years. Much of this time is spent with significant mental and physical disability and dependence.

Not surprisingly, Alzheimer's disease takes a significant toll on caregivers and families - physically, emotionally, and financially. Former President Ronald Reagan's daughter, Patti Davis, described losing her father to Alzheimer's disease as "The Long Goodbye". Families and friends say goodbye to an individual slowly over time as the disease gradually steals aware his/her memory and cognitive

functioning. In the most severe stage of the disease, nursing home placement is almost inevitable given the high cost and resources needed to keep someone in their home.

The financial burden of Alzheimer's disease and other dementias is high at an individual, family, state, and national level. Alzheimer's disease is one of the costliest chronic diseases to our society. According to the Alzheimer's Association, the national cost of caring for people with Alzheimer's and other dementias will reach $214 billion in 2014. Of these costs, it's estimated that Medicare and Medicaid will pay $150 billion (70%) for health care, long term care and hospice. The average per-person payments for health care services, e.g., hospital, nursing home, health care providers, are higher for Medicare beneficiaries with dementia than for those without dementia. The out-of-pocket spending for individuals with dementia and their families is expected to be $36 billion this year.

The national annual cost for caring for these individuals is rapidly increasing and is projected to reach $1.2 trillion by 2050. Unless we change the trajectory of Alzheimer's disease, the economic burden of this disease stands to overwhelm us all. I applaud the steps the federal government has taken in recent years to address this, including Congress passing the National Alzheimer's Project Act which led to the creation of the *National Plan to Address Alzheimer's Disease* by U.S. Department of Health and Human Resources in 2012. The Plan is designed to help those with the disease, their families, and caregivers today and work toward changing the trajectory of the disease in the future. But more is needed if we, as a nation, want to prevent and effectively treat the disease by 2025.

Meeting the Needs of Individuals with Alzheimer's disease, Families, Caregivers, and Providers in Frontier Montana.

While working towards changing the trajectory of the disease in the future, we need, at a community-, state-, and national-level, to deliver better care and support to individuals suffering with Alzheimer's disease and their families and caregivers today. As a physician who has practiced geriatric medicine for nearly thirty years, I continue to see the devastating effects of Alzheimer's disease and other dementias on my patients and their families and caregivers. I've watched health care providers, hospitals, medical clinics, community nursing homes and assisted living facilities and patient advocacy groups struggle to provide the comprehensive quality care and services these individuals and families require and deserve. Given the slow, progressive nature of this disease with its associated cognitive and physical disability and psychosocial issues, "it will take a village" to accomplish this. We need to develop effective, dementia-capable systems at the health care organization-, community-, and state-levels and find new strategies to provide high quality coordinated care, services, and programs to these individuals and their families and caregivers.

To help achieve this here in Montana, a number of concerned and motivated individuals have formed the Montana Alzheimer's/Dementia Work Group. This state-wide "grassroots" effort consists of a diverse group of individuals from across the state representing multiple industries or stakeholder groups including the National and state Alzheimer's Associations, Montana Office on Aging and other

government agencies, patient advocacy groups, patient advocates (caregivers), Assisted Living/Long-Term Care, senior services groups, regional healthcare organizations and providers, educators, and researchers.

The Work Group has tasked itself with identifying the challenges and gaps Montanans face when dealing with Alzheimer's disease and estimating its economic impact on our state. Using this information, over the next 12 – 18 months, we plan to develop a comprehensive Montana Alzheimer's Disease State Plan. This plan will serve as a state-specific roadmap to help inform our state government on critical dementia issues across the state. It will also provide a set of recommendations on how to improve and support Alzheimer's disease care and services and will outline what steps our state should take over a given timeframe to achieve key recommendations. Given the current and future impact of Alzheimer's disease on our state budget, e.g., Medicaid, we feel that developing and implementing a well-formulated state plan now will move Montana towards becoming a dementia-capable state and prepare us for the sweeping economic and social impact Alzheimer's disease will have on us all going forward.

To be prepared for the Alzheimer's disease public health crisis, Montana faces the same challenges as other states in the union. Alzheimer's can no longer be the "silent" or "hidden" disease. We need to increase public awareness about Alzheimer's and encourage early detection and diagnosis. We need to deliver community-based and residential dementia care services in an equitable, cost-effective manner. There needs to be better support for family caregivers to help alleviate their burden. Training programs for all health care providers, e.g., physicians, nurses, nurse practitioners, emergency department personnel, nursing home and assisted living staff, with a standardized curriculum need to be developed to ensure providers have the skills necessary to deliver coordinated dementia-capable care. In partnership with our federal and state governments and key stakeholders, we need to create "dementia-friendly" communities that locally provide high quality coordinated care, services, and programs to individuals with Alzheimer's and their families and caregivers.

Montana also faces unique challenges. Given its large land mass and small population, it is not only a rural state but also a frontier state. Rural and frontier communities struggle to recruit and retain primary care providers. They lack the community-based and residential dementia care services found in larger communities. For decades, one of our state's biggest exports has been its youth. This affects the availability of local family support to help someone inflicted with Alzheimer's. To ensure their care needs are met, many will need to be admitted to a local nursing home or leave their community to be closer to family. There is also a shortage of geriatric specialists across the state. Our work group and state will need to consider these unique challenges as we develop and implement an Alzheimer's Disease State Plan.

Conclusion

I would like to thank the Committee again for the opportunity to testify today and talk about our Montana Alzheimer's/Dementia Work Group initiative. I appreciate your interest in and efforts to address Alzheimer's disease going forward. It is clearly a prevalent, costly, devastating condition with

high morbidity and mortality. If the trajectory of the disease is not altered, by mid-century the economic and societal impact of this disease will be overwhelming. Likely all of us and our children will be impacted by it. Working in partnership, we all need to do what is necessary to achieve the goal of the National Plan to Address Alzheimer's Disease – to prevent and effectively treat Alzheimer's disease by 2025. As a physician who provides medical care for these individuals, I look forward to the day when I can offer effective preventive treatment options to my patients and their families. Thank you again for your time.

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DEPARTMENT OF HEALTH AND HUMAN SERVICES

STATEMENT OF

BRUCE FINKE, M.D.

ELDER HEALTH CONSULTANT
INDIAN HEALTH SERVICE

BEFORE THE

SPECIAL COMMITTEE ON AGING

UNITED STATES SENATE

FIELD HEARING ON

ALZHEIMER'S DISEASE:

A BIG SKY APPROACH TO A NATIONAL CHALLENGE

BILLINGS, MT

August 13, 2014

Good Morning Chairman Walsh and Members of the Committee. I am Dr. Bruce Finke, Elder Health Consultant for the Indian Health Service (IHS). I am also the IHS representative to the U.S. Department of Health and Human Services (HHS) Advisory Council on Alzheimer's Research, Care and Services. I am pleased to have the opportunity to testify before the Senate Special Committee on Aging on the impact of Alzheimer's disease and related dementias on American Indian and Alaska Native communities, and on the work being done in Indian Country to address this issue.

As you know, IHS plays a unique role in HHS because it is a health care system that was established to meet the Federal trust responsibility by providing health care to American Indians and Alaska Natives (AI/ANs). The mission of IHS, in partnership with AI/AN people, is to raise the physical, mental, social, and spiritual health of AI/ANs to the highest level. IHS provides comprehensive health service delivery to approximately 2.1 million AI/ANs from 566 Federally-recognized Tribes in 35 states. The IHS system is organized and administered through its Headquarters in Rockville, MD, 12 Area Offices, and 168 Service Units which provide care at the local level. In support of the IHS mission, health services are provided directly by IHS Federally-operated facilities, through Tribally-contracted and -operated health programs, through services purchased from private providers, and through urban Indian health programs.

Alzheimer's disease in Indian Country

While reliable prevalence or incidence data on Alzheimer's disease or other types of dementia in the American Indian and Alaska Native population are not currently available, we do know that in every Tribal community there are individuals with dementia and caregivers struggling to support them. IHS data from 2001 indicated death rates from Alzheimer's Dementia were approximately half of that of the U.S. All Races, but had risen dramatically in the previous 20 years in a pattern similar to that of the US All Races[1]. These data appear to underestimate the true prevalence of dementia in Indian Country. IHS workload statistics of a subset of IHS beneficiaries showed nearly 17,000 unduplicated patients with dementia between 2007 and 2013[2]. High rates of diabetes, cardiovascular disease, and traumatic brain injury indicate a high population risk for dementia. The experience of IHS clinicians suggests that dementia is under-recognized and diagnosed at later stages in American Indian and Alaska Native communities, even relative to the low rates of diagnosis in the nation as a whole.

From conversations with Tribal leaders, Tribal aging network providers, health care providers, and elders and their families over the past 15 years, we understand a number of factors that contribute to low rates of recognition and diagnosis. The strong tradition of extended family caregiving in Tribal communities often compensates for the decreasing function of the elder with dementia. Families may use traditional and cultural views of

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[1] Trends in Indian Health 2002-2003
http://www.ihs.gov/dps/index.cfm?module=hqPubTrends03

[2] Workload data derived from the National Data Warehouse, accessed July 25, 2014, for fiscal years 2007 – 2013.

aging to explain the changes associated with dementia, thus normalizing the changes rather than seeing them as a disease in need of treatment. Diagnosis of dementia across divides of culture and language can be challenging for clinicians, especially in the early stages of the condition.

Care for persons with dementia and support for their families requires care coordination and care management often beyond the capacity of many IHS, Tribal, and Urban Indian health programs. Caregiving challenges are amplified by the relative lack of formal long-term services and supports in Indian Country. Prior to 2010, Tribes took the lead in using their own resources or grants, contracts or reimbursements from other federal and non-federal entities to provide long term services and supports. The IHCIA reauthorization in 2010 provided new authorities for long-term services and supports to the IHS and to Tribes. The capacity of the local tribal and federal care systems to expand access to services remains a significant challenge to implementing these new authorities.

In response to a request for consultation on the implementation of the IHCIA, Tribes indicated that they would like to develop the long term services and supports that will allow elders to remain in their community as they age, regardless of disability. During IHS' annual budget consultation with Tribes, long term care services are discussed among the many other Indian health priorities.

National Alzheimer's Project

Much of the work to address Alzheimer's disease in American Indians and Alaska

Natives takes place within the context of the National Alzheimer's Project. On January 4, 2011, President Obama signed into law the National Alzheimer's Project Act (NAPA), requiring the Secretary of the U.S. Department of Health and Human Services (HHS) to establish the National Alzheimer's Project to:

- Create and maintain an integrated National Plan to overcome Alzheimer's
- Coordinate research and services across all federal agencies
- Accelerate the development of treatments that would prevent, halt, or reverse the disease
- Improve early diagnosis and coordination of care and treatment of the disease
- Improve outcomes for ethnic and racial minority populations at higher risk
- Coordinate with international bodies to fight Alzheimer's globally, and
- Create an Advisory Council on Alzheimer's Research, Care, and Services to create, review and maintain the National Plan and work on its implementation.

The National Plan was released by then HHS Secretary Sebelius on May 15, 2012. The Plan includes a detailed listing of current federal activities, and, as directed by the NAPA and the Advisory Council, recommendations for priority actions to expand, eliminate, coordinate, or condense federal programs.

The Plan was updated in April 2014 and describes the progress made throughout 2013 in the areas of research, care and supports, and interagency collaboration. It also includes updates to a number of the Plan's goals and strategies, reflecting the recommendations of the Advisory Council.

Indian Health Service Response and Partnerships

Through the National Plan to Address Alzheimer's Disease, the Indian Health Service is working with the Office of American Indian, Alaska Native, and Native Hawaiian Programs at the Administration on Aging (AoA) in the Administration for Community Living (ACL) around four person-centered goals for improving the care for and the lives of American Indians and Alaska Natives with dementia and their families. These goals are expressed as four statements that every individual with dementia should be able to make:

"I was diagnosed in a timely way."

Individuals and families need help recognizing cognitive impairment at its earliest presentation and should expect a timely and accurate diagnosis so that they understand what is going on, what to expect, and how to prepare.

"I know what I can do to help myself and who can help me."

Often persons with dementia and their families struggle in isolation to adapt and cope with the inevitable changes that this condition brings to their lives. They need reliable access to culturally appropriate information and to the resources available in their community to help them - both formal long-term services and supports and less formal support through peer-led groups such as those provided by the Alzheimer's Association and other similar groups.

"Those helping to look after me feel well supported."

Persons with dementia should know that their caregivers will receive the help and support they need.

"My wishes for care are understood and honored."

Individuals with dementia may not be able to express their wishes for care as the condition progresses. Those who have specific wishes or advance directives should have confidence that these wishes will be honored.

Our work on these goals builds on Indian Country strengths: strong families and a tradition of family caregiving, community-oriented primary care, committed and active public health nursing and community health representatives, and the Tribally operated aging network. The challenges in rural and frontier settings require significant coordination and service integration efforts to improve the lives of those with dementia across the usual boundaries of clinical and community-based services.

The IHS works with multiple partners to improve care for those with dementia. The IHS and ACL are working with the Department of Veterans Affairs (VA) to adapt and implement the evidence-based REACH (Resources for Enhancing Alzheimer's Caregiver Health) VA program of caregiver support in Tribal communities through both public health nursing and the Tribal aging network. REACH VA is an evidence-based translation of the REACH II behavioral intervention that uses structured interventions to provide caregivers of individuals with dementia with the tools and skills to manage ongoing problems that arise in the course of caregiving. The IHS is building on VA work to test strategies for early recognition among family members as well as clinical and aging services staff. Participation in the VA Dementia Steering Committee links the IHS to the approaches and tools in use at the VA to improve dementia care. The VA is also a

source of clinical expertise in diagnosis and management of dementia for the many Native Veterans who receive primary care in IHS and Tribal sites.

The IHS, ACL, and the Centers for Medicare and Medicaid Services are working under a Memorandum of Understanding to coordinate and collaborate in the provision of technical assistance to Tribes in the development of long-term services and supports. Together we have developed a series of webinars and web-based technical assistance resources. We worked together in development of the CMS Money Follows the Person Tribal Initiative to build infrastructure to support home and community-based care for Tribes in states participating in that initiative. IHS and ACL are collaborating to provide training on Alzheimer's disease and related dementias for the Tribal aging network.

Most care for persons with dementia can and should take place in primary care. IHS, Tribal, and Urban clinics are building better primary care, improving access and continuity using our Improving Patient Care Initiative, which is our Patient-Centered Medical Home model. In IHS, we have expanded participation in our Improving Patient Care Initiative from 38 sites in 2009 to 172 sites in 2014 which is helping improve coordination of care for patients. Increased funding for Purchased and Referred Care (formerly Contract Health Services) has allowed IHS and Tribal programs to gain access to referrals for specialty services that support the provision of primary care in IHS facilities.

Increasing awareness and recognition of dementia in Indian Country starts with access to quality care and meaningful support for individuals with dementia and their caregivers in Tribal communities. The IHS is committed to working in partnership with tribes, federal agencies, and community organizations to improve quality and access to care for individuals with dementia. We are working to change and improve the IHS, and these efforts will help us continue to strive to provide the best possible care for patients with dementia.

Thank you and I am happy to answer questions.

Statements for the Record

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TESTIMONY OF MAX RICHTMAN, PRESIDENT AND CEO
NATIONAL COMMITTEE TO PRESERVE SOCIAL SECURITY AND MEDICARE

UNITED STATES SENATE SPECIAL COMMITTEE ON AGING
HEARING ON "ALZHEIMER'S DISEASE: A BIG SKY APPROACH TO A NATIONAL CHALLENGE"

BILLINGS, MONTANA
AUGUST 13, 2014

My name is Max Richtman, and I am the President and Chief Executive Officer of the National Committee to Preserve Social Security and Medicare in Washington, DC. The National Committee is a grassroots advocacy and education organization dedicated to preserving and strengthening safety net programs, including Social Security, Medicare and Medicaid.

In my current position and as a former Staff Director of the Senate Special Committee on Aging, I especially appreciate the opportunity to testify today. I commend Chairman Bill Nelson, Ranking Member Susan Collins, Senator John Walsh and other members of the Aging Committee for holding this field hearing on Alzheimer's disease and related dementias. The Senate Aging Committee has a long history of highlighting the need to combat Alzheimer's disease and to provide assistance to family members and friends who are caring for someone with this devastating illness.

Many of us are aware of the great human and financial costs of Alzheimer's disease (AD) because we have family members or friends who are victims of AD or are caregivers for someone who is. The financial implications of Alzheimer's disease and related dementias on our nation's health care system, particularly the Medicare and Medicaid programs, which I have been asked to address, are also great. Without a cure for Alzheimer's disease, the cost of providing services to this population has the potential to consume federal and state health care budgets. My remarks include a brief discussion of the rising prevalence and cost of caring for people with Alzheimer's disease and related dementias, followed by recommendations for meeting these challenges.

Prevalence of Alzheimer's Disease

The number of people suffering from Alzheimer's disease or a related dementia is expected to skyrocket over the next few decades because people are living longer and the incidence of Alzheimer's disease increases with age. According to the Alzheimer's Association[1], currently

[1] Unless otherwise noted, the statistics referenced in this testimony are from the Alzheimer's Association report: 2014 Alzheimer's Disease Facts and Figures. http://www.alz.org/downloads/facts_figures_2014.pdf

there are over five million Americans, aged 65 and older (1 in 9), living with Alzheimer's disease or a related dementia. This number is expected to climb to as many as 16 million by 2050. It is estimated that by 2030, a person in the United States will be diagnosed with Alzheimer's disease or a related dementia every 33 seconds.

Montana will face a significant rise in the number of people with Alzheimer's disease. In 2014, there are 18,000 older adults living with Alzheimer's disease or a related dementia in the state. By 2015, this number is estimated to increase by 50 percent to 27,000 individuals.

The Cost of Alzheimer's Disease

As more people are diagnosed with Alzheimer's disease and related dementias, the cost to care for this population dramatically increases. In 2014, the cost of caring for people with Alzheimer's disease is estimated at $214 billion; by 2050, it will reach $1.2 trillion. This does not include the unpaid services provided by 15 million caregivers. In 2013, this cost for unpaid caregiving was valued at $220.2 billion. In Montana alone, 48,000 caregivers provided 54 million hours of unpaid care to people with Alzheimer's disease and related dementias, valued at $677 million.

The Medicare and Medicaid programs cover about 70 percent of the cost of caring for people with Alzheimer's disease and related dementias. In 2014, these two programs will spend an estimated $150 billion for health, long-term care and hospice care for people who have dementia and related disorders. And it is important to keep in mind that even with Medicare and Medicaid, individuals with Alzheimer's disease and related dementias pay high out-of-pocket costs for premiums and cost sharing as well as for health services not covered by public or private insurance. Costs are especially high for custodial care, which is not covered by Medicare and is only covered by Medicaid for low-income individuals. The out-of-pocket cost for treating Alzheimer's patients in 2014 is estimated to be $36 billion.

Medicare and Medicaid

Despite the fact that Medicare does not pay for custodial care, Medicare spending is impacted by Alzheimer's disease. It is estimated that Medicare spending per person is three times more ($21,095 vs. $8,005 in 2013) for beneficiaries with Alzheimer's disease and related dementias than for beneficiaries without these diseases. These additional costs are due to the fact that people with Alzheimer's disease have more hospital stays, skilled nursing facility care, home health visits and hospice care than other Medicare beneficiaries. In addition, individuals with serious medical conditions such as coronary artery disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease, stroke and cancer who also have dementia use more health care services than people with these medical conditions without dementia.

Twenty-nine percent of older adults with AD and other dementias are dually eligible for Medicare and Medicaid, compared to 11 percent for those without dementia. About 1.5 million

people with dementia benefit from the Medicare payment assistance with co-pays and premiums that Medicaid provides to low-income beneficiaries.

Medicaid, which is a joint federal and state program, provides health insurance coverage to multiple low-income populations, assistance to low-income Medicare beneficiaries, long-term services and supports to seniors and people with disabilities and support to safety net hospitals and health centers. Some states receive home- and community-based waivers that allow them to provide additional resources to help seniors live in the community.

Individuals with Alzheimer's disease and related dementias rely heavily on Medicaid services. This is, in part, because the majority of nursing home residents (about two-thirds) have some form of cognitive impairment. In 2014, per person Medicaid spending for Alzheimer's disease and other dementias is, on average, about 19 times higher ($10,771) than Medicaid spending ($561) for people without dementia.

In 2014, Medicaid will spend about $37 billion for people with Alzheimer's disease and related dementias. By 2050, Medicaid expenses for this population are expected to climb by almost 400 percent, reaching $172 billion in 2050. These costs are likely to overwhelm many state Medicaid budgets.

Senate Special Committee on Aging

In 1983, the Senate Special Committee on Aging held a field hearing entitled, "Endless Night, Endless Mourning: Living with Alzheimer's."[2] The focus of the hearing was on caring for people with Alzheimer's disease but the Senators and witnesses discussed the same wide array of issues we are grappling with today – the need for increased funding for Alzheimer's research, how to pay for custodial long-term care and education and training for professional and family caregivers, and social supports for Alzheimer's victims and family caregivers.

Thirty years ago, when this hearing was held, we knew very little about Alzheimer's disease. Since then, research supported by the National Institute on Aging and other organizations has deepened our understanding of the disease and improved diagnosis. In addition, support for families and caregivers has improved.[3]

While I acknowledge and commend the progress that has been made, we are still waiting for a cure and/or a way to prevent Alzheimer's disease. At the Aging Committee's 1983 hearing, then-Senator Larry Pressler of South Dakota stated, "The point is, if we could find a cure or a treatment for this disease, we could save a lot of money, besides preventing the tragic losses involved."

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[2] U. S. Senate Special Committee on Aging, Hearing on "Endless Night, Endless Mourning: Living with Alzheimer's." New York, NY, September 12, 1983. http://files.eric.ed.gov/fulltext/ED246344.pdf.

[3] Alzheimer's Disease Fact Sheet, Alzheimer's Disease Education and Referral (ADEAR) Center, National Institute on Aging, National Institutes of Health, U. S. Department of Health and Human Services. September 2012. http://www.nia.nih.gov/sites/default/files/alzheimers_disease_fact_sheet_0.pdf.

Without a cure for Alzheimer's disease and related dementias, millions of Americans will continue to suffer the devastating effects of these illnesses into the foreseeable future. Not only does this take a huge emotional toll on their lives, but it also places a severe financial burden on them and their families, and on the Medicare and Medicaid programs.

Recommendations

The National Committee to Preserve Social Security and Medicare urges Congress to adopt the following recommendations to help meet the challenges that Alzheimer's disease presents and to lessen the economic impact it has on families and government programs:

- **Invest more federal funds into Alzheimer's disease research to find a cure and/or a way to slow down the progression of the disease.** This would save millions of lives and curb rising Medicare and Medicaid costs associated with Alzheimer's disease and other dementias.

- **Build on the reforms in the Affordable Care Act (ACA) that contain costs and promote access to high-quality care.** This includes coordinated care, such as Accountable Care Organizations and medical homes, which improve care for beneficiaries with multiple chronic conditions including Alzheimer's disease. The National Committee believes we can strengthen Medicare's financing and improve the quality of care provided without cutting benefits.

- **Establish a long-term services and supports social insurance program**. People need assistance in paying for custodial care without having to impoverish themselves or their spouses.

- **Encourage states to expand their Medicaid programs under the Affordable Care Act.** Expansion would benefit younger seniors under age 65, enabling low-income people diagnosed with early onset dementia to receive Medicaid benefits.

- **Provide caregiver credits under Social Security**. Temporary interruptions in a person's participation in the labor force to care for an individual with Alzheimer's disease can result in a reduction of Social Security benefits upon retirement. Providing caregiver credits would help make up for the time family members are away from employment for their caregiver duties by increasing their Social Security benefits.

- **Boost Social Security benefits; do not cut them.** In addition to helping individuals, it is important to recognize the positive economic impact Social Security has on state and local economies, including Social Security payments that go toward helping pay the cost of in-home or institutional care that is not covered by Medicare or Medicaid.

Thank you for the opportunity to testify today on the important topic of combating Alzheimer's disease for both humane and financial reasons. These issues and all they encompass are critically important to the millions of members and supporters of the National Committee to Preserve Social Security and Medicare and to all Americans.

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