Moderator: **Massachusetts State Representative Danielle Gregoire**

Panelists: **Dr. Catherine Freiman, Medical Director, Alzheimer's, Biogen**
Jennifer Rosen, Director of State Affairs, Alzheimer's Association
Minnesota State Senator Carla Nelson

Voiceover: Welcome to the Women In Government Podcast. Whether discussing important issues or policies of the day, this is the place where lawmakers and decision-makers unite to get the conversation started.

Representative Danielle Gregoire: According to the World Health Organization (WHO), tens of millions of people worldwide live with Alzheimer's disease, and that number is expected to grow in the coming years, outpacing the healthcare resources needed to manage it and costing billions of dollars.

Hello, I'm Representative Danielle Gregoire from Massachusetts. On this episode of the Women In Government Podcast, we're going to be focusing on "Alzheimer's Disease: The Importance of Early Detection & Diagnosis."

Quality care for people with Alzheimer's disease and other dementias starts with an early, documented and disclosed diagnosis. However, less than 50% of people with dementia are diagnosed, and of those who are, less than 50% are told.

Early detection and diagnosis offer a number of benefits to help people who have Alzheimer's or dementia and their families, and is even more important given breakthrough disease modifying therapies could be on the horizon.

As you hear, it's important for states to consider policies that promote early detection and diagnosis - including public awareness programs and health care professional education and training - and ensure continued accountability to create the infrastructure necessary to address this growing public health crisis.

Joining in on the conversation is Dr. Catherine Freiman. She is a Medical Director of Alzheimer's at Biogen, a Massachusetts-based biopharmaceutical company with its global corporate headquarters in Cambridge, Massachusetts, which focuses on neurological diseases with high unmet need including Alzheimer's, ALS and Parkinson's. Thanks for joining us.

Dr. Catherine Freiman: Thank you for the invitation. I'm delighted to be here.

Representative Danielle Gregoire: We also have Jennifer Rosen. She is the Director of State Affairs at the Alzheimer's Association.

Jennifer Rosen: Thank you, Representative Gregoire. Alzheimer's Association has been a long-time partner with Women In Government, and we just really appreciate that WIG offers these opportunities to talk about timely issues with all of our nation's women leaders. Thank you.

Representative Danielle Gregoire: Finally, we have State Senator Carla Nelson from Minnesota joining the panel. The Senator, who represents the Rochester and Mayo Clinic area, was first elected to the Minnesota House in 2002 and then to the Senate in 2010, 2012, and 2016. She was just re-elected in 2020. In the current session, she chaired the Education Finance & Policy Committee and served on the Health and Human Services Finance & Policy Committee. Senator Nelson will chair the Tax Committee in 2021. Throughout her time in the Minnesota legislature, she has championed various Alzheimer's legislation.

Senator Carla Nelson: Thank you so much for having me. This is such an important issue. It's truly the disease of our generation, and I so look forward to our conversation. I thank Women In Government for the forum to get this important information out to legislators throughout the nation.

Representative Danielle Gregoire: Before we get started, I'd like to thank everyone for listening. Don't forget to subscribe to, like, or share this podcast. You can also find out more by visiting https://www.womeningovernment.org/.

Nationally, more than five million people are living with Alzheimer's, and by 2050 this number is projected to almost triple. It's important to note that the majority of Americans over age 65 with Alzheimer's or dementia are women. The disease is also the sixth-leading cause of death in the U.S., and the fifth-leading cause of death for seniors. As the population of our country ages, Alzheimer's is taking the lives of more and more people.

Dr. Freiman, can you tell us more about the disease and its various stages?

Dr. Catherine Freiman: Alzheimer's disease is a progressive neurological condition that impairs thinking, memory, and independence, eventually leading to premature death. It's characterized by changes in the brain, including the accumulation of toxic amyloid beta plaque, which begins approximately 20 years before patients exhibit symptoms of the disease.

Important to note is that Alzheimer's disease is a continuum, beginning with pre-clinical Alzheimer's disease (AD) and progressing to mild cognitive impairment, or MCI due to AD, and then mild AD, moderate AD, and eventually severe AD. MCI due to AD is one of the earliest stage of the disease when symptoms start to be more visible, and MCI can be detected and diagnosed.

Current research efforts are focused on catching and treating patients as early as possible for the best chance of slowing or stopping the progression of Alzheimer's disease.

Representative Danielle Gregoire: Thank you, Dr. Freiman. Jennifer, you have referred to Alzheimer's disease as a public health crisis. Can you talk more about the economic and social burden associated with this disease?

Jennifer Rosen: Yes, thank you. It wasn't too long ago that "The New England Journal of Medicine" labeled Alzheimer's as "the most expensive disease in America," and they did that because of the cost of care and the burden on families really is just so high. In 2020 alone, total payments for individuals with Alzheimer's or other dementias are estimated to be $305 billion dollars – and that's not including all the other unpaid caregiving that happens.

Medicare and Medicaid are expected to cover about $206 billion dollars – or 67% of the total healthcare and long-term care payments for people with Alzheimer's. And out-of-pocket spending? That's expected to be about $66 billion – again, just this year alone for people living with Alzheimer's and other dementias.

When we're talking about Medicaid, average per person Medicaid spending for seniors with Alzheimer's or other dementias is 23 times greater than the average per person Medicaid spending across all seniors without dementia. And again, just in this year alone in 2020, it's estimated that caring for people with Alzheimer's will cost Medicaid an estimated $51 billion dollars, and that will rise nearly 300% - and think about that even before inflation - by the year 2050.

As we know, Medicaid is really appropriated in state budgets, and that's why we work so closely with our state officials across the nation in seeing how we can really tackle these costs and address this public health crisis.

When you think about these numbers, again with the cost being so high and where the costs are coming from, total payments for healthcare, long-term care, and hospice care for people with Alzheimer's and other dementias is projected to increase to $1.1 trillion dollars in 2050, and that figure is in 2020 dollars, so it's pretty high. Total lifetime costs of care for someone with dementia is an estimated $357,000 in today's dollars, so costs are substantial, and the only way we can really tackle this is if we accepted that this really is a public health crisis.

Representative Danielle Gregoire: Thank you for that. When we hear those numbers and relate them to the disease, and then add the human factor, we see just how much of a crisis this really is. I'd like to focus some time on those who love and care for people living with Alzheimer's. Jennifer, can you tell us a bit about caregiving?

Jennifer Rosen: Absolutely. Last year, caregivers of people with Alzheimer's and dementia provided an estimated 18.6 billion hours of unpaid care, and when you look at the value of what that unpaid care is, if we were actually paying those caregivers, that contribution is valued at about $244 billion dollars. These are husbands, wives, sons, daughters, mothers, aunts, partners, spouses who are providing this care at their own expense to their own health and their own income to care for their loved ones.

Nearly half of all caregivers – about 48% - who provide help to older adults do so for someone with Alzheimer's, so the burden on caregivers specifically with this disease is astronomical. So, adding to that, labeling Alzheimer's as a public health crisis and thinking about it – we're not just talking about the individual living with the disease but we're talking about the caregivers as well.

Approximately 2/3 of caregivers for people living with Alzheimer's and other dementias are women. 1/3 of dementia caregivers are daughters, so our partnership and work that we engage with Women In Government on is really meaningful as we work with women leaders in many states around the nation to address this issue.

And then one last thing that always comes to mind, 41% of caregivers have a household income of $50,000 or less, so there is a great expense all around to those families who are caring for loved ones with dementia.

Representative Danielle Gregoire: Thanks, Jennifer. Senator Nelson, you have been a champion on Alzheimer's issues in the state of Minnesota. Why is this disease important to you?

Senator Carla Nelson: Well, thank you for the important question. As we heard from our previous commenters, clearly Alzheimer's is a public health crisis. It's really the disease of our generation. And then as a financial person who directs state spending, Alzheimer's has an impact on state spending. States pay half of Medicaid spending, and so, that astronomical increase in the numbers of U.S. citizens who have Alzheimer's and the care and the cost that goes with that will bankrupt our states and our federal government as we seek to pay for those astronomical costs.

There's a public health reason to be involved. Of course there's a financial reason to care very much about this issue, and then there's the personal issue as well. I'm one of those daughters of an Alzheimer's patient. My father had Alzheimer's disease, and we lived through that – kind of knowing that my dad was exhibiting some symptoms, and then in 2012 there was that confirmation that confirmed what we all dreaded. And it's that early confirmation that can help families, caregivers, and the loved one with Alzheimer's to best know how to plan for that.

So, Alzheimer's is a disease that we cannot forget about. We have to have this front and center. It is a national crisis – financially, for public health, and personally as well. Most people know someone who has Alzheimer's or someone who has passed away with Alzheimer's, so it's critically important, and I'm just to thankful for the discussion today to speak about that.

Representative Danielle Gregoire: Thank you, Senator. Dr. Freiman and Jennifer, can you discuss some of the benefits of early detection and diagnosis?

Dr. Catherine Freiman: Due to the progressive nature of Alzheimer's disease and other dementias, the best opportunity for individuals to benefit from available treatments and to enroll in clinical trials and importantly build a care team is in the early stages of the disease.

Jennifer Rosen: Senator Nelson actually just alluded to the importance of care planning and the struggles on that front. For individuals who are aware of their diagnosis and their caregivers, if they have this diagnosis in hand as early as possible, they can plan for the future by creating advanced health directives, making really important financial and legal arrangements before their cognition significantly declines, and they can also address safety issues and seek counseling to cope with the changes that are coming down the road.

The care planning is just as important for the family caregivers as it is for the individual living with the disease, so there's lots to be done.

Senator Carla Nelson: Just to tag onto that, that diagnosis also helps with the social interactions as well, and it helps really with the spouse who might be living with that person. Understanding that the person you loved, married, have lived with for 50 or 60 years is seeming a bit different and knowing that it is Alzheimer's I think helps give those family members that extra knowledge to love every minute that you have no matter what the situation is. You love every minute that you have with that special loved one who has Alzheimer's.

Representative Danielle Gregoire: Thank you for that, Senator. For early detection to occur — and subsequent diagnosis and disclosure awareness — individuals and physicians must overcome several barriers. Jennifer, can you discuss some of the barriers that exist?

Jennifer Rosen: This is a real challenge for us. This is a real challenge for our families living with dementia. We hear sometimes that it can take up to 2 years for someone living with dementia to get a diagnosis, and it's not until they get a diagnosis that they can start engage in that care planning that we talked about – the legal decisions, different support services they may need to access depending on what stage of the disease they're in.

That's not to mention a lot of burden and heartache for the family as they're living through what's happening with their loved one and aren't quite sure is it dementia or is it not dementia and also seeking that support they might also need as a caregiver.

So first and foremost, the lack of diagnosis is a huge barrier, and we think about the emotional stress, the physical stress. Without that diagnosis, families may not really be addressing some of the very urgent things that are happening or changes that might be happening in their loved one – things like wandering, safety concerns in the home. There's lot to be considered.

There are barriers with physicians, and we're starting to make some headway here, but there's a lot of work to be done. We talked quite a bit about the importance of early detection and diagnosis and public awareness and removing the stigma from a diagnosis. Oftentimes we'll hear sometimes from a physician, "You know, this person is in the later stages of the disease. What's the point of the diagnosis

because they can't really do anything about it anyway?" "Why worry the individual living with the disease?" "Why worry their family unit?" That's a barrier. That's a stigma we have get past.

And then we have to get past the stigma of people being afraid to talk to physicians or family caregivers even mentioning something to a doctor on an annual wellness check if there loved one isn't, and encouraging that they take some signs more seriously and being open and communicating about these signs. It's really important that all healthcare providers, nurses and physicians alike, have access to the most up-to-date information about how to detect Alzheimer's and understanding and knowing those early signs of dementia.

Representative Danielle Gregoire: Public policies can help promote early detection and diagnosis – such as raising public awareness of the signs of Alzheimer's and the education and training of health care providers – which can ultimately support health outcomes of those living with the disease and other dementias.

Senator, with regard to public awareness, you have spearheaded legislation to increase public awareness and understanding of Alzheimer's. Can you speak more about this?

Senator Carla Nelson: In 2015, I authored the [Alzheimer's Research and Support Act, Senate file 247](#), and part of that was born out of my personal experience with my father. This bill required that the Minnesota Board of Aging implement a public awareness program to promote those benefits we've talked about here – those benefits of cognitive testing, awareness of Alzheimer's disease and other dementias, and then awareness of the needs of the caregivers, which we've talked about today as well.

I'm happy to say that some of those provisions in the bill passed, and I'm very glad to tell you today that I'll be the lead sponsor of the Alzheimer's Public Awareness Program bill that will be filed in the Senate. It has bipartisan support, and it will be filed in 2021 in the Minnesota Senate.

The bill also established a statewide dementia grant program, and that's important to support regional and local projects and initiatives that are targeted to a designated community which could consist of a specific geographic area or a population. The point is to increase the awareness of Alzheimer's disease and other dementias and also increase the rate of that cognitive testing in the populations at risk for dementia, and then of course to promote the benefits of early diagnosis so the family members will not be afraid and will reach out to their medical providers as they start to see some signs that might cause them to think their loved one may have dementia.

It's very important to connect the caregivers of those with dementia to education, and different communities have different educations. Here in Rochester, we have a [HABIT](#) (Healthy Action to Benefit Independence & Thinking) program that really helps educate the family members and helps them as they love their loved ones through this journey of Alzheimer's and help them. So, it's very important regarding the caregivers as well.

The grants and the funding for them were signed into law by Governor Dayton. We still have yet to do, though, that all-important statewide public awareness program, and that's the bill that will be filed here in 2021 in the Minnesota Senate.

Jennifer Rosen: And if I may jump in, I'd like to give a little bit of extra thanks and gratitude and kudos to Minnesota and to Senator Nelson because the establishment of that grant program – one thing that's unique and since that program was established in 2015 is really looking to address health inequities as well and get to the topic that really all of us in the healthcare space are focusing on and zeroing in on which is health equity.

That grant program does work to target underserved communities and diverse communities. That's really important when we're talking about diagnosis and we're talking about cultural competency and public awareness campaigns and removing the stigma and when we're talking about reaching underserved communities who may not have access to care providers and we're talking about clinical trials.

So, kudos to Minnesota for being a leader in this space on the public awareness front. Thank you, Senator Nelson, for championing that.

Representative Danielle Gregoire: Dr. Freiman, your company Biogen is based in Massachusetts, where just last session we passed comprehensive Alzheimer's legislation that I authored with early detection and diagnosis provisions such as requiring healthcare physician training. Can you tell us more about this?

Dr. Catherine Freiman: Biogen's Government Affairs team worked with the Alzheimer's Association Massachusetts and New Hampshire chapter and other advocates to pass legislation signed by Governor Baker as Chapter 220 of the Acts of 2018. Of note, through this legislation, Massachusetts was the first state to require that physicians, physician assistants, registered nurses, and practical nurses who serve an adult population complete a one-time course of training and education as part of granting or renewing a license on the diagnosis, treatment, and care of patients with cognitive impairments including but not limited to Alzheimer's disease and dementia.

As of August 2020, around 51,000 Massachusetts clinicians have confirmed that they have taken a satisfactory training course.

Representative Danielle Gregoire: Right now, the Alzheimer's therapies on the market mostly control or reduce symptoms of the disease. However, research has developed to a point where scientists can look beyond treating symptoms to think more about addressing underlying disease processes in future therapies. The prospect of new, breakthrough therapies that could meaningfully change the course of the disease further underscores the importance of policies to promote early detection and diagnosis.

Dr. Freiman, Biogen is at the forefront of Alzheimer's research and has filed a Biologics License Application (BLA) for a therapy that I still can't pronounce (aducanumab), which is currently undergoing priority review at the FDA. Can you tell us more about this, including how to correctly pronounce it?

Dr. Catherine Freiman: Sure! Aducanumab (add-you-can-uh-mab) is an investigational human monoclonal antibody studied for the treatment of Alzheimer's disease. We had two phase 3 studies entitled "EMERGE and ENGAGE," and these studies were multicenter, randomized, double-blind, placebo-controlled, parallel group studies – all of those standards that make a great study – and they were designed to evaluate the efficacy and safety of Aducanumab.

Based on the clinical data from patients with mild cognitive impairment due to Alzheimer's disease and mild Alzheimer's disease, Aducanamab has potential to impact underlying disease pathophysiology as well as slow cognitive and functional decline and provide benefits on patients' abilities to perform activities of daily living which include things like conducting personal finances; performing household chores such as cleaning, shopping, and doing laundry; and independently traveling out of the home.

The FDA is expected to issue a decision on the application by March 7, 2021, and if approved, Aducanumab would be the first treatment to clinically change the course of the disease for individuals living with Alzheimer's.

Representative Danielle Gregoire: A treatment that prevents, cures or slows the progression of Alzheimer's could result in substantial savings to the U.S. health care system. Without changes to its structure, however, access to new treatments for the disease may be severely restricted by capacity restraints. Based on the findings of a 2017 RAND Corporation study, the U.S. health care system is ill-prepared to handle the potentially high volume of patients who could benefit from a treatment that reduces clinical decline for Alzheimer's disease.

Dr. Freiman, as companies like yours are working to bring disease modifying therapies to patients, can you talk about the health care infrastructure challenges raised?

Dr. Catherine Freiman: Sure. The RAND study described a couple of bottlenecks to patients getting diagnosed early, and the first one is at the point of early diagnosis. After patients are screened positive for mild cognitive impairment by healthcare professionals such as primary care physicians, they are referred to a dementia specialist. In the United States, dementia specialists consist of neurologists, geriatricians, and geriatric psychiatrists. These specialists do not have enough capacity to evaluate all MCI patients, so to ensure an open pathway of Alzheimer's disease diagnosis and treatment, the healthcare system needs to invest in increased training of dementia specialists.

Additionally, to appropriately identify people living with the early stage of Alzheimer's disease, a biomarker test is required either via positron emission tomography, or PET scan, or cerebral spinal fluid test, or CSF, to confirm the presence of beta amyloid, one of the hallmarks of Alzheimer's disease. To

maximize access for treatment for patients with early stage Alzheimer's disease, diagnostic pathways for PET and CSF need to be increased in the United States.

Representative Danielle Gregoire: Alzheimer's will continue to be a large and growing public health crisis that state policymakers cannot ignore. Senator Nelson, what are ways in which states can keep Alzheimer's and dementia at the forefront?

Senator Carla Nelson: There are many things to do. One, if it's not happened already, every state should establish a work group of state officials – those would be your public health professionals, the Board of Aging, Social Services, Medicaid, advocacy stakeholders, professional caregivers, and family members who are experiencing this with their loved ones – so establish that working group.

And then, advance legislation or state agency directives so that we make sure to implement that state Alzheimer's disease plan, and that would look to establish accountability. It's good to designate a state agency to lead in the implementation of the state plan. They are responsible.

Then, implement state policy changes as are recommended in the state plan, and that would include establishing an infrastructure that serves the needs of those with the disease and their caregivers and look to help communities be dementia-friendly communities.

For example, in 2017, I was the chief author of [Senate File 120](#), which established the Alzheimer's Disease Working Group, and this bill was also enacted as part of a larger omnibus bill and signed into law by Governor Dayton. This Alzheimer's Disease Working Group has then been used and has updated Minnesota's state plan for Alzheimer's disease because we know the disease is not stopping. It is growing.

We have more citizens who will have Alzheimer's disease, but fortunately, we also have more and newer innovations and research just like the medication that Biogen is hopefully getting to market here soon. We want to make sure that our state plans are updated with those new innovations as well.

Representative Danielle Gregoire: As we wrap up, I'd like to offer some time for closing comments. Dr. Freiman, why don't we start with you?

Dr. Catherine Freiman: I'd just like to thank everyone and all the organizers for hosting this program and for inviting Biogen to describe our efforts to develop a treatment for Alzheimer's disease, and most importantly, for bringing attention for this important topic.

Representative Danielle Gregoire: Jennifer, do you have anything to leave our listeners with?

Jennifer Rosen: I do, thank you. Senator Nelson really hit on those key policy solutions and things that we can be doing at the state level to change the trajectory of how we're responding to this public health

crisis. Each one of those policy solutions that she referenced are so critical – that state plan work, the coordinated response from state governments is so critical.

Our nation is in the midst of a massive healthcare workforce shortage, and when you're talking about the early detection and diagnosis of Alzheimer's and other dementias, a number of states have been labeled as neurology deserts. We actually have a massive shortage of neurologists, of geriatricians, primary physicians, and the list goes on.

When an effective treatment comes to market, we need to be doing what we can to make sure our health systems are ready and prepared and that we find ways to fill the gap in the workforce shortages and also ensure that the workforces really receive enough specific training. The way you engage with someone who has dementia – whether they're in the early stage of the disease or the late stage of the disease – requires a unique training and understanding of how to communicate with someone living with dementia and what their needs are around the behavioral symptoms, and this extends to every facet of our healthcare workforce.

So, it's going to be incumbent upon a very coordinated state-federal government response, and within state governments, coordination between all the different agencies through that state work that Senator Nelson referenced that brings all the key stakeholders in a state together for a coordinated response. We've got a lot of work to do, and I really appreciate the time here today to join you all to talk about this timely issue.

Representative Danielle Gregoire: And finally, Senator Nelson?

Senator Carla Nelson: I just want to thank Women In Government for this forum. For the Alzheimer's Association and all of our guests, this is so critically important. We cannot lose sight of the growing public crisis of Alzheimer's and also then take hope in the light of those new innovations and those new technologies and those new pharmaceuticals that can help our loved ones live with Alzheimer's and can help caregivers as they care for their loved ones .

I am so thankful for the opportunity to bring this forward and to share and to learn from other legislators in other states too about what has happened to advance Alzheimer's care, research, and support.

Representative Danielle Gregoire: As we've heard, quality care for people with Alzheimer's disease and other dementias starts with an early, documented and disclosed diagnosis.

Early detection and diagnosis offer a number of benefits and is even more important given breakthrough disease modifying therapies could be on the horizon.

Once again, I'd like to thank our panelists for providing such incredible insights. It's inspiring to hear the promise that both science and policy can bring to improve the lives of people living with Alzheimer's or related dementia.

I'd also like to thank all the listeners for taking the time to hear this important discussion. Don't forget to subscribe to, like or share our podcast. You can also email us by visiting https://www.womeningovernment.org/.

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