



**Pennsylvania House Hearing on
Alzheimer's Disease and Related Disorders Office Infrastructure
June 3, 2024**

Let me begin by acknowledging and thanking Chairwoman Madden, Representative Mentzer and Members of the House Aging and Older Adult Services Committee, for convening this hearing on the Alzheimer's Disease and Related Disorders (ADRD) Office Infrastructure. Thank you as well to those of you, including Representative Khan, Representative Venka and others who have championed dementia related issues throughout the year. I appreciate you providing Drs. Lopez and Weeden, Alzheimer's Association Advocate, former caregiver and nurse, Jennifer Davis, and I with this opportunity to speak about the latest approaches in dementia care, importance of this infrastructure, and the critical needs of the individuals, families and communities impacted by dementia across the commonwealth. I would also like to thank Governor Shapiro, Secretary Kavulich, Secretary Bogen and the administration for their budget proposal to provide support for these important efforts. Through prior discussions and testimony like today's, the administration and all the members of the Pennsylvania General Assembly have an opportunity to show true leadership in seeking to address the Alzheimer's crisis in Pennsylvania.

I am Kristina Fransel, Executive Director of the Alzheimer's Association Delaware Valley Chapter, and for the past 25 years, I have worked in the voluntary health field, helping to drive care, support and access to care for those impacted by chronic diseases—both patients and their caregivers. As we've heard from Drs. Lopez and Weeden, we are at a pivotal moment in the field of Alzheimer's and dementia. For the first time in decades, there are treatments available for patients that target the underlying biology of Alzheimer's dementia, and we know there are more in the pipeline. Beyond that, disease research is happening at any given moment around the world that will feed the pipeline, investigate genetic risk, test biomarkers as a method for diagnosis, and explore all aspects of dementia and its impact from the lab through clinical practice. What's more, we know—with more certainty than ever before—that addressing Alzheimer's and dementia in the community will require a coordinated, public health approach, specifically one that addresses risk reduction, early detection and diagnosis, and provides support for patients and their caregivers. This work spans government agencies, private entities, community organizations and more. Thank you, Dr. Lopez and Dr. Weeden, for sharing your perspectives and expertise with us today.

As we think about where we are and where we are going, we have to first reflect on where we have been—what has led to this point. More than ten years ago, this conversation began.

In 2013, the Alzheimer's Disease Planning Committee was established after Executive Order 2013-01 was signed by Governor Corbett. Twenty-six members including Dr. Lopez were appointed to the committee, and in 2014, the Pennsylvania State Plan for Alzheimer's Disease and Related Disorders was created and approved. As many know, the plan provided seven strategic recommendations to address the then current needs and to prepare for an expected rise in Alzheimer's and dementia in Pennsylvania.

That was a tremendous moment for Pennsylvania, and it offered hope to those impacted by Alzheimer's and dementia and their caregivers, as well as to those supporting and caring for patients in a health care setting.

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But progress in the years since the ADRD State Plan was created has been stymied with most priorities remaining unaddressed and impacted by many factors, most notably a lack of funding support and a lack of coordination across government agencies providing services and support.

Across the Commonwealth, numerous state agencies administer a variety of programs that are critical to people living with dementia and their families, but they can be siloed, each working independently from one another, and often they're offering services and support much too late in the disease experience. As a whole, Pennsylvania has failed to understand and embrace the significance of public health practice throughout this Alzheimer's disease continuum that agencies like the CDC, NIH and others have advocated for for a decade and—which Dr. Weeden has so clearly described as the necessary path forward.

We cannot change that or regain those opportunities but we can now look into the future, at the potential impact of dementia if the Commonwealth continues on this same path of limited accountability, structure and funding.

Between 2020 and 2025 it is estimated that the number of people aged 65 and older in Pennsylvania who are living with Alzheimer's will jump by nearly 15 percent. As of 2020, the Medicaid cost of caring for someone with Alzheimer's is \$3.7 billion—a number expected to increase by more than 10 percent by 2025. And in Pennsylvania, the number of Medicaid and Medicare recipients with dementia has grown every year, from 37,052 in 2015 to 58,342 in 2020—imagine another 57 percent increase by 2025, and another 57 percent jump by 2030.

These meteoric rises in prevalence, impact, and cost will only continue if there is not a systematic and coordinated approach to address dementia much earlier in the disease continuum. Our time today does not provide enough opportunity to look deeply into everything from risk reduction and early detection to navigating care, enhancing care quality and more but this legislation provides expertise and accountability to do just that across a wide span of related issues.

We all understand the numbers, the projections, and the trajectory of the disease. But where this work becomes more salient, where it has the most impact, is in the community—directly affecting lives of constituents who are impacted by Alzheimer's and dementia.

If we think ahead toward 2030, we anticipate biomarker testing for Alzheimer's will be a standard practice in the clinic. We anticipate more treatment options for patients in the early stages of the disease. We anticipate research results will demonstrate further evidence that early intervention will delay or prevent cognitive decline (Resource: U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk [[U.S. POINTER](#)]). And we anticipate better testing and health care provider training and education will strengthen brain health practices, improve early diagnosis, and deliver better dementia care navigation where healthcare is delivered—broadly across our communities.

The future of dementia care is on the precipice of profound, positive change for those in other states. But Pennsylvania must do more to prepare for what's ahead, and to ensure this hopeful future becomes a reality for its citizens.

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At present, our Pennsylvania constituents face obstacles every single day as they navigate the current systems—whether government systems or health care systems. There are barriers to diagnosis that have ripple effects into many aspects of life for a patient and a caregiver. There are barriers to accessing respite services for caregivers who are experiencing their own fatigue and who may be neglecting their own health as a result of the caregiver burden. And there are obstacles in planning for the day-to-day and long term care needs of those living with dementia.

For instance, Mike Stanford—an Alzheimer's Association volunteer advocate from Adams County, who is in the room with us today—spent two years and visited four different providers with his wife, Marcia, only to be told Marcia “likely” had Alzheimer's disease. By contrast, Marcia had also been diagnosed with breast cancer—her diagnosis came one day after her annual mammogram. Within two weeks, Marcia had a lumpectomy, she was scheduled for radiation, and had been prescribed a medication regime to follow. When it came to cancer, Marcia had a care plan, a support system within the health care setting to help navigate next steps, and nearly instant access to medications and treatments. And Mike, once a husband, a partner to Marcia, was now a caregiver. He also had a full time career, and children to care for. Mike now managed his life and needs, those of his kids, the needs of Marcia—current and future—and he was left to navigate care options—both sourcing and affording—financial and estate planning, social security bureaucracy, insurance processes, health care needs and appointments, and more.

Mike and his family relied on more than 70 members of their community—friends, family, neighbors—to help care for and look after Marcia. What Mike needed was a coordinated system, one that worked together to help him and his family navigate this disease—from the point of concern, to diagnosis and treatment, to care and support, to end-of-life planning.

Stanford's experience is not uncommon. In fact, it's exactly the situation many Pennsylvanians are facing right now. It's an experience of difficulty getting a diagnosis. It's an experience of complicated care navigation and unaffordability. And it's an experience of limited resources at all points of the disease experience.

There is also the experience of George and Mary Ellen Buckbee, of Lackawanna County, who are here today. Mary Ellen is living with younger-onset Alzheimer's and George is her full time, primary carepartner. Following Mary Ellen's diagnosis the two began wading through their options, what treatments might be available, how they might afford medications, where they might be able to access them, and what processes, protocols and paperwork would be needed. Mary Ellen began receiving Leqembi for the treatment of her disease, but to do so, she had to travel hours to Philadelphia for her infusions. This year, Mary Ellen became the first person to receive this treatment in Scranton just minutes from her home.

And while treatment might seem like a positive element of the Buckbee's Alzheimer's experience—as they agree they have seen helpful impacts since beginning treatment—the barriers to getting a diagnosis and accessing the medication, coupled with the logistical and administrative burden that came with navigating the process, fell on the shoulders of George. He was left to put the pieces of Mary Ellen's care and support plan together, on his own, without the support of a cohesive system.

And finally there is the experience of Jennifer Davis, Alzheimer's Association volunteer advocate and Nurse Practitioner, of Delaware County, which she will share today. Jennifer dedicated herself to providing care for her mother, Linda, and to ensuring—to the best of her ability—that her mom lived her final years

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with love and dignity. Yet despite her commitment, and her professional experience caring for medically complex patients, considering their future care needs, and assisting with coordination of services or resources after discharge, as a caregiver, Jennifer still faced obstacles in our current system.

These are examples of real, personal experiences from residents of the Commonwealth which clearly illustrate the need for a cohesive ADRD office infrastructure, and yet these are just a few of the more than 747,000 Pennsylvanians with a diagnosis and their family members providing care, even before we talk about the workplaces, faith communities, care providers and others who are impacted. Every single day there is another Mike and Marcia Stanford, another George and Mary Ellen Buckbee, and another Jennifer and Linda Davis.

Without action, the Commonwealth risks falling even further behind in addressing the needs of constituents.

The Alzheimer's Association is dedicated to serving and supporting those across the Commonwealth who are impacted by Alzheimer's and dementia, and we are committed to being the voice for those in need. We understand there is much work to be done within the state government to bring the ADRD Office Infrastructure to life.

We also know that since the State Plan's inception, efforts to sustain meaningful implementation have been slow-moving or incomplete. Different administrations, agencies and community providers have done what they can but with little to no resources, infrastructure or accountability measures in place to support this critical work, it is an uphill battle.

Over the last decade, the Alzheimer's Association, our volunteer advocates and other organizations have worked with new and longstanding bipartisan champions—some of whom are in the room today. Our Pennsylvania advocates have demonstrated perseverance with state lawmakers to secure passage of legislation to improve early detection and diagnosis for all Pennsylvanians, and together we have drawn from their families' painful stories to demonstrate the need for a comprehensive approach to address dementia as a public health issue. In fact, the very nature of this disease means that a number of those who worked on the original plan are no longer with us. These individuals, who could have benefited most, did not see meaningful implementation of this work during their lifetimes. Continued delays will not only add to that, but it will ensure the Commonwealth lags even farther behind what was laid out a decade ago and cement Pennsylvania's lack of preparation for the advancements that have already been discussed today.

We all collectively have a chance to change that now. This important legislation would provide a framework for state governments and other stakeholders to consider and advance dementia care issues that currently fall across different departments, agencies, stakeholders and communities. An ADRD infrastructure within the State government will streamline response to those affected by Alzheimer's and dementia giving patients and their caregivers coordinated support.

The Alzheimer's Association understands and appreciates the work that is being done across the state, some of which is having an impact across the country but is yet to be realized in our own backyard. Notably, the work of the Alzheimer's Disease Research Center (ADRC) at the University of Pittsburgh, led by Dr. Lopez, as well as the ADRC at the University of Pennsylvania, and a number of other research

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centers in Pennsylvania, are having profound impacts in advancing research and clinical practice nationwide. But translating those advancements into practice and ensuring all Pennsylvanians can benefit will only be more difficult without a more cohesive government infrastructure and strategic plan. As we heard from Dr. Weeden, initiatives like the BOLD Public Health Program, can change the trajectory for Pennsylvania's most vulnerable. We know there is much more to be done in a coordinated and rigorous way—and this work begins with support from our State Legislators so we can, at all levels, serve, support and meet the needs of our constituents across the Commonwealth—now and for years to come.

Thank you Chairwomen Madden and Members of the House Aging and Older Adult Services Committee for the time and for the invitation to be here with you today.

Respectfully Submitted,



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