

Testimony of Yvonne Latty

The Path Forward: Advancing Treatments and Cures for Neurodegenerative Diseases

United States House of Representatives Subcommittee on Health of the Committee on Energy and Commerce

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Chairwoman Eshoo, Ranking Member Guthrie, and Distinguished Members of the Committee, thank you for the opportunity to share my family's story during today's hearing.

I am journalist and college professor at New York University, but I sit here before you because my mom, Ramona Latty, a Dominican immigrant, has advanced Alzheimer's disease and lives in a nursing facility in the Bronx. She is 88. I am her only living child.

This disease is rampant in my community. In general, Latinos are [1.5 times](#) more likely than non-Latino Whites to develop Alzheimer's disease.¹ (My chances of getting the disease are also slightly elevated because my mother has it.) The health issues that plague our community—high blood pressure, heart disease, diabetes and stroke—make us more vulnerable. The statistics for the African American community are even worse; they are two times more likely to get the disease than white folks.

But this disease is not who my mother is, even though it has taken control of her. My mom was born in Santo Domingo, a city on the coast of the Dominican Republic. She grew up poor. In the eighth grade, she had to drop out of school to take care of her brother, so that her mother could work. My mom was a big dreamer who wanted more: She wanted out of Santo Domingo, where she worried she'd live a life with no work, no money and no hope.

In 1950, my mom immigrated to New York. Coming to America was her dream come true. She worked in factories and went to beauty school. She met my dad, Albert, a child of Jamaican parents, at a beauty parlor in Spanish Harlem where she worked. They were married nine months later and had two daughters: me and my big sister Margie. My dad and my sister have both died. And so it has been us two for a long time.

About six years ago my mother started to show signs of dementia. She was losing things and was confused. Then she began to hallucinate a boy who lived on top of her refrigerator. I discovered she gave all of her money away to mail-order psychics, who promised her riches. We spoke every day, sometimes multiple times a day. I found myself thinking about her all the time, worried.

So we turned to her doctor, who suspected dementia and referred us to a neurologist. I remember the day we went to his office in the Bronx, where Black and Brown people packed the waiting room. After a series of tests, he told us dryly that she had Alzheimer's disease. He gave me some URLs, told me to Google it, and sent us on our way in less than 10 minutes. It was clear he had no time for us; he barely looked at my mom. I went home and cried.

This is not uncommon in the Latino community. Despite a higher risk for Alzheimer's, Latino and Black Americans face steep inequities in accessing a formal diagnosis. According to a recent study of Medicare beneficiaries, Black Americans (18.2%) and Latinos (15.8%) were less likely to receive a timely diagnosis when compared to Non-Hispanic Whites (23.3%).ⁱⁱ

But I was ready to fight this disease. I switched neurologists, and the new one referred her for a clinical trial to help with the hallucinations.

While Latinos make up roughly 17% of the U.S. population, they [make up less](#) than 2% of the participants currently enrolled in Alzheimer's research funded by the National Institute of Health.ⁱⁱⁱ Clinical trial enrollment represented hope against a disease that is often seen as a death sentence. I was thrilled that she was going to be a part of one, and hopeful that it could help her.

But it was grueling. She lived in the Bronx, and I had to get her to New York-Presbyterian Hospital in Washington Heights every week for six weeks. She had to visit a series of doctors and have a psychological exam before the medicine was administered. We barely had enough compensation to cover an Uber from the Bronx to the research site.

Research accessibility in communities like the Bronx is a systemic issue. According to an analysis by the University of Wisconsin, the geographic distribution of the nation's 31 federally funded Alzheimer's Disease Research Centers – marquee research sites – “skews toward the most wealthy neighborhoods.”^{iv}

Balancing her research participation and my full-time job was another challenge. I was teaching and had to ask my co-workers to cover me so I could be at every appointment. I was able to make it work because my employer offers paid family and medical leave and flex time, but millions of Americans are not so lucky. Paid leave is an urgent health equity issue for dementia caregivers.

According to a national survey of employed dementia caregivers, less than half have access to paid family and medical leave policies like me. More than half of caregivers (55%) who utilized paid family and medical leave benefits reported it resulted in better emotional well-being, compared to 23% of caregivers who didn't have access to these benefits.^v

Having this flexibility was critical as my mother's care become more complicated. She had to take the medicine at a certain time, but she couldn't take it on her own; plus, she only had a part-time aide, and so I had to scramble for more help. It was exhausting—and in the end, she got the placebo version of the trial drug. After all that, the treatment hadn't done anything. And there was not much else they could do but wish us luck and send us on our way.

Despite the initial engagement and our interest, we were never contacted again about opportunities to participate in a clinical trial.

Things continued to get worse. Soon, the boy above the fridge was joined by a new hallucination: ICE. I would get frantic late-night calls that a black ICE van was circling the block around her apartment, and she would beg me to help her. They were coming to deport her, she

said. I tried to tell her that they couldn't take her away; she was a naturalized citizen. Finally, her aide found her wandering in the street one morning. She was no longer safe. She needed 24-hour care, and I had to place her in a nursing home.

It was the hardest thing I ever had to do in my life.

So now after living through a pandemic, in which every floor of her nursing was infected with COVID-19, after a year in which my mother further declined, she is now nonverbal and can no longer feed herself --and every day I wait for the call that says she is passing... I am asking your committee to think of her, me and so many others like us who journey through this disease.

So here is what I am respectfully asking on her behalf.

Improve equity in diagnosis and detection of Alzheimer's:

Early and accurate diagnosis of dementia is central to improving the delivery of health services and care, yet healthcare providers are under-equipped to make an accurate and timely diagnosis. In fact, studies have found that approximately 40 percent of patients with dementia are unrecognized in the primary care setting.^{vi}

Representatives Linda Sánchez, Darin LaHood, Doris Matsui and Fred Upton have introduced the Concentrating on High-Value Alzheimer's Needs to Get to an End (CHANGE) Act (H.R. 3354 / S. 1692) to encourage early assessment and diagnosis of Alzheimer's disease and related dementias.

The CHANGE Act would improve the Welcome to Medicare and Annual Wellness Visit preventive benefits and ensure Medicare providers fulfill the detection of cognitive impairment requirement in a more effective manner by requiring providers to use screening tools designed to detect cognitive impairment and signs of Alzheimer's or dementias in the early stages. The legislation directs the Centers for Medicare and Medicaid Services (CMS) to require the use of cognitive impairment detection tools identified by the National Institute on Aging during the Medicare Annual Wellness Visit and would add detecting cognitive impairment as a requirement of the "Welcome to Medicare" benefit. It also includes payment measures which incentivize the detection and diagnosis of Alzheimer's disease or related dementias and discussion of appropriate care planning services, including potential for clinical trial participation.

I ask the Committee and other members of Congress to support this bill to improve the barriers to an early and accurate diagnosis of dementia. I believe this type of legislation would help put an end to the "Google It" approach that many providers are taking today.

Improve equity in Alzheimer's clinical trials:

The underrepresentation of people like my mom in Alzheimer's research, and of Asian and Native Americans, could limit our understanding of how new drugs and treatments might work in high-risk populations. Representatives Lisa Rochester, Jaime Herrera Beutler, John Curtis, Chris Smith, and Maxine Waters introduced the bipartisan Equity in Neuroscience and

Alzheimer's Clinical Trials (ENACT) Act (H.R. 3085 / S. 1548), to increase the participation of underrepresented populations in Alzheimer's clinical trials by expanding education and outreach to these populations, encouraging the diversity of clinical trial staff, and reducing participation burden, among other priorities. I ask the Committee and other members of Congress to support this bill to increase the accessibility of Alzheimer's research to people of color at greater risk of Alzheimer's.

Further, I encourage the committee to examine the financial incentives available to participants to overcome barriers. From what I experienced, the hurdles for the poor to participate are too great.

Establish a paid family and medical leave policy to help families navigate work and medical care:

Over the past year, millions of family caregivers have found themselves scrambling to fill gaps in care—often without paid leave—as many older adults and people with disabilities lost access to services. Like me, many people are sandwiched between providing care for a loved one living with a chronic disease like Alzheimer's and raising children.

A national policy on paid leave can help alleviate challenges facing working family caregivers who often struggle to be in two places at once: at home providing daily critical care needs to those who rely on them and at work supporting their employees and co-workers and earning an income. I encourage the committee to support efforts to establish a national paid family and medical leave policy by supporting the Building an Economy for Families Act, introduced by House Ways and Means Committee Chairman Richard E. Neal.

Support a National Alzheimer's Prevention Goal:

Recent research confirms that a significant percentage of dementia, which ranks the top of fears of aging Americans, could be delayed - and in some cases prevented - by early intervention. In fact, studies indicate that more approximately 40 percent of dementia cases are potentially preventable by addressing risk factors including hypertension, diabetes, depression, physical inactivity, poor nutrition, smoking, hearing loss, traumatic brain injury, sleep, and social isolation and loneliness.

This is a hopeful message that not many Americans or health providers are aware of. That's why I urge the committee to ask the Department of Health and Human Services (HHS) to establish an ambitious national goal to prevent Alzheimer's disease and related dementias. This call for a national prevention strategy is widely supported. More than 190 national organizations, including the including Volunteers of America, the American Federation of Teachers, American Heart Association, National Urban League, YMCA of the USA, AARP, UnidosUS, the National Kidney Foundation, the Southern Christian Leadership Conference, HADASSAH, the Milken Institute and others are calling for a national dementia prevention goal and a plan to reach that goal that includes metrics to measure progress along the way, and a focus on healthcare equity that recognizes the disproportionate impact of this disease on communities of color and women.

ⁱ Alzheimer's Association. (2021). Race, Ethnicity and Alzheimer's in America. <https://www.alz.org/media/Documents/alzheimers-facts-and-figures-special-report.pdf>

ⁱⁱ Tsoy E, Kiekhofer R.E., Guterman E.L., et al. (2021). Assessment of Racial/Ethnic Disparities in Timeliness and Comprehensiveness of Dementia Diagnosis in California. *JAMA Neurol*. Published online March 29, 2021. <https://doi.org/10.1001/jamaneurol.2021.0399>

ⁱⁱⁱ Development of an NIA Practice-Based Research Network to Conduct Alzheimer's and Related Dementias Clinical Research. (2021). National Institute on Aging.

^{iv} Powell WR, Buckingham WR, Larson JL, et al. Association of Neighborhood-Level Disadvantage With Alzheimer Disease Neuropathology. *JAMA Netw Open*. 2020;3(6):e207559. doi:10.1001/jamanetworkopen.2020.7559

^v UsAgainstAlzheimer's. (2018, September). A New Frontier in Paid Leave: Supporting Family Caregivers Providing Alzheimer's and Dementia Care. https://www.usagainstalzheimers.org/sites/default/files/2018-09/A_New_Frontier_In_Paid_Leave.pdf

^{vi} Chodosh J, Petitti DB, Elliott M, et al. Physician recognition of cognitive impairment: evaluating the need for improvement. *J Am Geriatr Soc*. 2004;52(7):1051-1059. doi:10.1111/j.1532-5415.2004.52301.x