

STATEMENT OF DR. WHITNEY WHARTON
ASSOCIATE PROFESSOR, EMORY UNIVERSITY

Cures in Crisis: What Gutting NIH Research Means for Americans with Cancer, Alzheimer's, & Other Diseases

U.S. SENATE FORUM

March 26, 2025

Senator Baldwin, Senator Welch, and distinguished members of the Senate— thank you for having me today. My name is Dr. Whitney Wharton, and I am a cognitive neuroscientist. The focus of my research is Alzheimer's disease prevention, specifically identifying mechanisms contributing to Alzheimer's disease like vascular risk factors and inflammatory markers in blood and in spinal fluid among individuals who are at high risk for Alzheimer's disease. My research has been funded by NIH for 18 years through postdoctoral and career development awards, as well as R level research grants for high-risk-high-reward and independent research projects. I conduct observational studies and clinical trials, all of which enroll participants from under resourced groups including women, Black Americans, the LGBT+ community, and individuals with a family history of Alzheimer's. I am an associate professor at Emory University and my remarks here today represent my own views and don't necessarily represent those of my employer.

I am here today as a scientist who has had 2 NIH grants abruptly terminated in the past month. On February 28th my first NIH grant was terminated, which had only 6 months remaining on a 4-year award. My terminated projects were scientifically sound, supported by strong pilot data, underwent rigorous peer review, and were developed in response to a specific NIH initiative. For example, the specific funding announcement at the time read, "Diversity among research participants broadens scope and improves the generalizability of scientific investigations. Classifications of race, ethnicity, socioeconomic status, sex/gender are multifactorial and dynamic in their influence on disease state, warranting their abundant representation in research."

While these terminations are devastating for me and my team, particularly junior faculty and students, my primary concern is for the patients, research participants and the families who are already being impacted by the NIH's recent radical shift in funding priorities.

These funding cuts are already having real world impacts. My research participants are adults with a parent with Alzheimer's disease. I'll call one of them Ms. Smith. Ms. Smith's mother was diagnosed with Alzheimer's disease six years ago. Ms. Smith was forced to quit her job to take care of her mother full time. She moved into her mother's house a year ago, where she sleeps on the couch, which is situated close to the front door, because her mother wanders at night. In her free time, Ms. Smith chooses to be a research participant, because she wants desperately to help her mother, and she is scared because she knows she is at increased risk for Alzheimer's herself. However, what scares her most is that her eldest daughter will have to care for her, the same way that Ms. Smith cares for her mother. Ms. Smith was supposed to have a research study visit next week, and news that this project is cancelled will devastate her.

Research involving patients and research participants cannot take place without trust. Building and retaining a group of patients and participants who donate their time, their energy, and quite literally

their blood, particularly when they have, or are at risk for a terminal illness is a gift, and the only way we can ensure effective treatments and prevention strategies in the future. Furthermore, research participants should be representative of the individuals most likely to have a particular condition. Research shows that Alzheimer's is more prevalent in women, racial and ethnic minorities and LGBT+ communities.

Termination of my peer reviewed grants, and hundreds of others, which were awarded based on merit, has potentially devastating implications for all Americans. It sets a concerning precedent where scientific inquiry and peer reviewed and awarded projects are turned off and on based on a set of changing priorities. Not only can this cause confusion, but it could also impact the pipeline of new and talented young investigators, and erase entire communities of patients, who are the most impacted by diseases like Alzheimer's, from research entirely.

Thank you again for having me here today.



**ALS Association
ORAL STATEMENT FOR THE RECORD
for the**

**UNITED STATES SENATE
Forum on**

**“Cures in Crisis: What Gutting NIH Research Means for Americans
with Cancer, Alzheimer’s, & Other Diseases”**

**March 26, 2025
Washington, DC**

For further information contact:
Melanie Lendnal
Senior Vice President of Advocacy
mlendnal@als.org

Good afternoon, Senator Baldwin and Senator Welch, thank you for the opportunity to speak today.

My name is Jessie Ybarra. I am a father, grandfather and military veteran from San Diego. I am also a person living with ALS.

ALS, also known as Lou Gehrig's Disease is a neurodegenerative disease that takes away a person's ability to walk, talk, and breathe. It is always fatal. For reasons still unknown, veterans like me are twice as likely to get this disease. The average survival time is only 2-5 years. Current treatment options for ALS are extremely limited and there is no cure – yet. But we are getting close.

That is one of the reasons I am deeply concerned about the proposed cuts to federal funding for ALS research and how it would harm me and the 30,000 other Americans living with ALS who depend on the commitment of public research.

The National Institutes of Health (NIH) and other federal agencies have been critical in funding groundbreaking research that offers hope to thousands of individuals like me, including by providing access to experimental treatments for ALS.

The experimental drug I am taking could not only extend my life but could also lead to a cure. Access to this drug could mean seeing my son and grandson graduate high school and college, something I did not think was possible when I was diagnosed.

But now funding cuts and reductions to funding at NIH and other research agencies threaten to derail decades of progress right when we are at the tipping point of finally finding a cure.

But to be clear, this isn't just about me, and everyone else impacted by ALS now and in the future. ALS costs our nation over one-billion dollars a year. Investing in finding a cure is not only fiscally responsible, but very simply, good public policy.

I urge Congress to reject these harmful cuts to NIH and support the funding necessary to make ALS a livable disease and cure it. My life, our lives, and our economy depend on it.

I would like to add to my statement. My son, Dewey has also shared his thoughts on the importance to NIH funding for ALS research.

[play audio]

Thank you, Senator Baldwin and Senator Welch, for your commitment and support to these critical issues. I am so grateful to have people like you fighting so hard for me and everyone else facing the diseases that NIH is trying to cure.

Written Testimony of Dr. Larry Saltzman

Congressional Forum: “Cures in Crisis: What Gutting NIH Research Means for Americans with Cancer, Alzheimer's, & Other Diseases”

106 Dirksen Senate Office Building

Wednesday, March 26, 2025

2:30-4:30 ET

Senator Baldwin, Senator Welch, and members of the forum — thank you for the opportunity to speak with you at this critical time. I’m deeply grateful that you’re holding this important discussion and shining a light on the very real consequences of undermining the research that so many Americans depend on. It means a great deal to be able to share my story with you today.

My name is Dr. Larry Saltzman. I am a former family physician, a former healthcare IT entrepreneur, a patient advocate, and a 15-year survivor of chronic lymphocytic leukemia and small cell lymphocytic lymphoma. I am also a grateful participant in six clinical trials, and perhaps most remarkably, a man who has survived ten relapses, two CAR T-cell therapies, an allogeneic bone marrow transplant, and more than a dozen different treatments. In every one of those phases, NIH-funded research has played a critical role in keeping me alive.

When I was diagnosed in 2010, my physicians told me I could expect to live another five to eight years. That kind of estimate is something patients with cancer know all too well — the “expiration date.” At the time, it didn’t feel real. But I quickly learned that living with a diagnosis like mine means constantly building bridges — from one treatment to the next — hoping each one holds long enough for research to catch up with your disease.

Because of research made possible by the NIH, I have crossed many of those bridges. And I’m here today, fifteen years later, because scientists built them in time and allowed me to outpace the cancer.

Because my disease kept changing, I needed treatments that hadn’t yet been approved. So I enrolled in clinical trials — six in total. Four of those therapies are now FDA-approved. That’s the pace we need and NIH support is what makes it possible.

The current administration’s threat to dramatically reduce or delay NIH funding from many of the most talented researchers and clinicians in the United States represents a crushing blow not only to the development of future cancer therapies, but to all medical research. The uncertainty is already making it harder for researchers to plan, collaborate, and deliver the breakthroughs patients urgently need.

For patients waiting on the next treatment, time is everything. These cuts could rob us of the time we need most.

Even with every advantage – my background in medicine, a national network of expert clinicians, and the financial resources to access clinical trials – surviving this disease was never easy. But most patients don't have those advantages, and, without NIH support, many simply cannot afford to participate in clinical trials even when it may be their only hope. For them, NIH funding is the difference between a chance and no chance.

I speak here today not only for myself, but for every patient who has ever held out hope that research would buy them another year — or another decade. Without robust, sustained, and predictable funding from the NIH, those bridges to the next treatment won't be there when patients need them.

The bridge that saved me was built through decades of investment, innovation, and relentless commitment from our nation's scientific community. But those bridges don't build themselves.

I am living proof of what NIH research can do, and I don't think I would be here today without the commitment that Congress has shown by prioritizing NIH funding over the past many decades. I ask you to protect this funding — so that more people can outlive their expiration dates.

I'm also proud to have shared my personal story through the Cancer Progress Report that the American Association for Cancer Research (AACR) issues each year. AACR plays a leading role in advocating for strong, sustained investment in biomedical research, and their recent statement responding to the administration's actions adequately reflects what so many in the scientific and patient communities are feeling right now — that we must speak out, stand up for science, and protect the future of medical progress.

Thank you again for giving me the chance to share what that progress has meant in my life. I don't take a single day of it for granted.

MONICA M. BERTAGNOLLI, MD

FORMER DIRECTOR, NATIONAL INSTITUTES OF HEALTH

Cures in Crisis: What Gutting NIH Research Means for Americans with Cancer, Alzheimer's, & Other Diseases

U.S. SENATE FORUM

March 26, 2025

Senator Baldwin, Senator Welch and distinguished members of the Senate:

Thank you for allowing me to speak at such a critical time for our nation. I am Monica Bertagnolli, a surgeon and cancer researcher who served as the 17th Director of the National Institutes of Health. I have had a full spectrum medical career. As a surgeon, I cared for patients with cancer. I conducted research to identify better ways to diagnose, treat and prevent cancer and led programs to educate the next generation of doctors and researchers. Most recently, I was a public servant responsible for overseeing how precious taxpayer dollars are used to improve our health. But I think that my most relevant role is that I am a cancer survivor. I would not be here today, healthy and thriving, without the research funded by NIH over the past 5 decades. So I also represent the many millions of people throughout our Nation who have directly benefited – even owe their lives – to biomedical research funded by the NIH.

I resigned my post as NIH Director in January of this year. Since then, I have had no insight into how decisions are being made by our current leaders at HHS. I can speak, however, about the downstream effects of their decisions, and some irreparable damage that their policies are producing. To date more than 300 grants terminated; and about \$1.5 billion in funding delays and barriers that are preventing NIH's role of ensuring that funding is delivered to outstanding researchers across the nation.

I recently met with a young researcher affected by current funding delays. He's not that young – 35 years old and just starting out after completing college, medical school, a PhD in molecular biology, a residency in internal medicine and special training in oncology. His mother died of pancreatic cancer and he wants to treat people with this deadly disease and conduct research to develop ways to prevent it. He trained for 16 years after high school in the best programs in the country, and today he can't find a job. Academic medical centers across the nation, the only places where the kind of care and research he has trained for are done, are under hiring freezes because research funding has been stopped, and institutions have no assurance that it will be restored. What will he do? He might seek a job in private industry, but this won't allow him to treat patients and will take away his chance to pursue fundamental research toward his goal of preventing the disease that took his mother. He might move to another country. This is not an isolated story. There are so many other damaging effects from funding cuts and delays, and the current situation, even if temporary, is producing irreparable harm, especially to those of

the next generation and not just in a few targeted research areas. We are losing the promising future work of this doctor and also those who might replace him – because how can we ask a young person who needs a career to sustain them to undertake the years of study required when the future is so uncertain?

Our country's investment in biomedical research has fueled tremendous progress. Consider the two biggest causes of death in our country – cardiovascular disease and cancer. Since I began my own career, the age-adjusted death rate from cancer in the US fell by 34%. That means 4.5 million people who would have died from cancer survived due to NIH-funded advancements in treatment, early detection, and prevention. Death rates due to heart attacks and strokes also fell by about 30% during this time. This progress would not have happened without taxpayer support. This same support also fueled our economy. In 2024, every \$1 of NIH funding generated an estimated \$2.56 in economic activity, amounting to \$94 billion in total for our economy. This funding produced over 400,000 jobs nationwide, and fueled local economies through spending on research-related goods, services, and salaries.

Today, we are just beginning to see progress against devastating diseases which have long been hopeless – Alzheimer's disease, diabetes, even pancreatic cancer – all because of NIH funding. And this has proven to be a great investment for American taxpayers – producing both extraordinary improvements in health, and significant profits for our nation's economy. How can we afford to see this progress stalled? Overall, the loss to our nation on so many levels will be too great.

Thank you.

STATEMENT OF DR. STERLING JOHNSON, Ph.D.

Cures in Crisis: What Gutting NIH Research Means for Americans with Cancer, Alzheimer's, & Other Diseases

U.S. SENATE FORUM

March 26, 2025

Ranking Member Baldwin and distinguished Senators, thank you for inviting me to be here today. On behalf of the University of Wisconsin's School of Medicine & Public Health, I am honored to participate in today's forum. My name is Sterling Johnson. I have a PhD in Clinical Psychology, I am a professor at the University of Wisconsin where I study diseases of the brain such as Alzheimer's.

I'm here to emphasize the critical importance of NIH funding in the fight against Alzheimer's—a disease that is one of our greatest public health and economic challenges. While deaths from heart disease and cancer have leveled off or declined thanks to decades of NIH investment, deaths from Alzheimer's and related dementias have increased. Over 6.9 million Americans live with Alzheimer's today—a number projected to double by 2050 without effective solutions.

Thanks to NIH support, our field has made game-changing advances. Two decades ago, we had no accurate way to diagnose Alzheimer's other than clinical judgement. The definitive diagnosis was possible only after death by looking at the brain under a microscope at autopsy. Today, we can detect the disease using brain imaging scans and new blood tests that identify the abnormal proteins driving the disease. These tools were developed and validated in part with NIH funding-- and then used in clinical trials that led to the first generation of FDA-approved treatments that robustly remove amyloid plaques from the brain and slow symptoms.

These biomarker tests also revealed something profound: Alzheimer's begins years if not decades before signs of memory loss. That insight was gained because NIH-funded longitudinal studies exist to draw on; and that insight has now been the basis for launching major NIH-funded prevention trials. Just last week an exciting study reported that extended treatment with an experimental therapy in a PREVENTION clinical trial demonstrated that progressing from normal to having cognitive impairment was cut in half. This is an extraordinary breakthrough and NIH-funded.

At the University of Wisconsin where I do research, NIH grants support a range of essential research programs. I'll briefly highlight two:

- **The Wisconsin Registry for Alzheimer's Prevention (WRAP)** is a long-running study tracking biomarkers and memory changes in people starting in midlife. It's helping us map out the 20-year silent phase of Alzheimer's and identify when and for whom prevention therapies might work best.
- **The Wisconsin Alzheimer's Disease Research Center (ADRC)** is part of a nationwide network that functions as a consortium and provides data to the world and local infrastructure for scientist for things like patient recruitment, advanced brain

imaging, and biomarker testing. These centers create efficiency by enabling scientists to do more definitive studies with center resources than what they could do if siloed in their own labs.

- We also participate in a national longitudinal study called the Alzheimer's disease neuroimaging initiative whose data have been freely used thousands of times and in partnership with big pharma to understand the progression rates of Alzheimer's and plan the next generation of clinical trials.

These are just some examples of many programs at our universities that are being conducted in a coordinated way with NIH oversight; these discoveries are changing the way we diagnose and treat Alzheimer's and related causes of dementia. But now we need to talk about how to sustain these hard fought substantive gains.

Over the last few months I have seen signs that are cause for concern.

- There are delays in the review and funding process for some projects and centers.
- There are proposed cuts that threaten major ongoing studies, including treatment trials, risking the loss of millions of dollars already invested and setting back our patients.
- On top of this there is growing uncertainty that is discouraging early-career scientists from staying in the field—undermining the future of our biomedical workforce.

If these cuts go into effect, studies will be delayed and slowed--we will lose ground on hard-won progress. Every setback costs lives and quality of life—and increases the already staggering \$345 billion dollar annual cost of Alzheimer's care.

Back in 2011 The National Alzheimer's Project Act (NAPA) set a bold stretch goal: to prevent and effectively treat Alzheimer's by 2025. We've made extraordinary gains—approved therapies that remove the plaques in the brain, accurate diagnostics, and a stronger understanding of disease biology—but we're not done by any means. NIH has overseen and closely coordinated this highly successful national response.

Federal investment in biomedical research via NIH has made the United States the global leader in medical innovation. By generating knowledge and technology that saves lives, we also create jobs, and drive economic growth including multiple public private partnerships. In 2023 alone, every \$1 of NIH funding generated \$2.46 in economic activity for our nation.

Ranking Member Baldwin and distinguished Senators, the progress of the past two decades has been nothing short of remarkable, thanks to bipartisan support. Our patients who have this progressive disease don't have the luxury of time to shoulder the unnecessary delays and uncertainty that we are currently experiencing. The clock is ticking for them and their families. Now more than ever we need the continued full resolve and commitment of the federal government to meet their need.

Thank you.