Former Obama staffer with ALS helps pass law for ALS patients to get quicker access to drugs

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Brian Wallach can only move two fingers, but that's not stopping him from using his voice.

Steadily, he taps out missives on why patients of ALS, or amyotrophic lateral sclerosis, deserve to use whatever short time they have remaining to make their own decisions on drugs. The disease causes motor neurons to degenerate, causing paralysis and eventually death. Since his 2017 diagnosis at the age of 37, he and his wife, Sandra Abrevaya, have fought to improve treatment and the possibility of a cure for patients like him.

In December, they watched as President Joseph Biden signed into law the Accelerating Access to Critical Therapies for ALS Act, or the ACT for ALS, which will help patients access drugs that could prolong their lives. The couple hopes it could even help Wallach, who like many is not eligible for clinical trials for reasons including being too far out from his diagnosis.

"Today, we're finally closer than ever to new treatments and hopefully, hopefully—God willing—a cure," Biden said as he signed the law. "And it's because of the movement led by the patients and caregivers." Mentioning Wallach and Abrevaya directly, who both worked for the Obama-Biden White House, Biden said, "They turned their pain into purpose."

The law authorizes $100 million annually to fund research into rare neurodegenerative diseases like ALS and expands access to drugs for patients suffering from ALS. Congress still needs to allocate funds.

For Wallach and Abrevaya, it's one more way they hope they'll have more time together.

The Kenilworth, Illinois, couple retains the same banter that's always made them magnetic for the ALS cause—a young couple of two small daughters fighting for him to have more time to watch them grow up.

Since his diagnosis, the couple has worked to spur momentum to make ALS something other than the quickly lethal disease it remains. Although the Ice Bucket Challenge created awareness of the disease in 2014 by raising more than $100 million, for the about 5,000 people diagnosed a year it remains a diagnosis of two to five remaining years of life.

Wallach and Abrevaya know this firsthand. They heard the letters "ALS" related to them for the first time in 2017, after tremors in Wallach's hand became a diagnosis of ALS. The former Obama staffers have since marshaled their ability to build coalitions and momentum toward extending patients' lives.

Wallach retains his undiluted positivity—often shown in appreciation-of-life moments on his popular Twitter account—and drive toward changing what he calls a "currently terminal illness." He and Abrevaya, who met working on the Obama administration years ago, remain partners in the fight of what both described to congressional lawmakers as "our closing argument for our lives."

"This bill will enable us to help the current generation living with ALS hopefully become the first generation to actually live longer than the average," Wallach said, "hopefully become the first generation of survivors."

The disease is slowly taking away his ability to speak. His wife translates for him, patiently asking "say again?" or "one more time," as she repeats what he tells her. He still has control of two of his fingers, which he uses to text and type on his phone. "Brian is trying to change the world with two fingers," Abrevaya said.

Last year, he was able to get around with a walker sometimes, and slowly make it up stairs on some days. "I've gone from being able to do calls on

my own to having Sandra help translate for me, and as you can see it is hard," Wallach said.

Although life has shifted, what he wants to say in those conversations has never changed.

Last year, they again used organizing skills built during the Obama years as they urged patients to reach out to lawmakers. The first time Wallach testified before a committee, one lawmaker was present. The most recent time, their testimony was late in the evening, after all the questions lawmakers were asking.

Constituents in every state reached out to lawmakers to set up Zooms, giving congressional representatives a personal understanding of what it's like to live with a fatal diagnosis.

Drugs can routinely take years to be fully approved, time in which advocates say patients could join clinical trials instead of waiting years they don't have. Many don't live long enough to qualify for access to some of the drugs under development.

Patients have long argued that facing a terminal diagnosis, they should be the ones to decide if they take experimental drugs.

Many who are excluded from clinical trials want to use the months or years they may have remaining to take a chance a drug could help instead of losing that chance completely—dying before it's officially approved.

One of those patients is Sarah Gascoigne, 28. She has had 20 family members diagnosed with ALS; it is only now that her family has begun to see the diagnosis as something where some might continue to live.

When she was diagnosed herself after noticing an aching calf in 2020, she immediately began to think about what this meant she could not do—get married, have children.

"We forever have just been told, you have your time, go do what you want with it, there's sort of nothing that could be done," she said.

Instead, Gascoigne has been in a clinical trial that seems to be helping, the first in her family in such a position. Although she's no longer able to run, she can still walk and does so daily. She's dating. "My life's not over," she said. "It really drastically flipped for me my outlook and my perception of what this is going to look like for me and my future."

For so long, she said, ALS has been known only as a death sentence. She said it's important for people to see and believe it could be something else.

"The ACT for ALS is going to be a game changer," she said. "It's very encouraging. There's literally been nothing like that."

The law should affect diseases beyond ALS. It created a partnership led by the Food and Drug Administration and the National Institutes of Health to develop and review drugs for rare neurodegenerative diseases. It also requires the FDA to publish a five-year action plan regarding drugs that improve or extend the lives of these patients and directs the federal Government Accountability Office to report on this to Congress.

Boosting research into neurodegenerative diseases could help people with illnesses like frontotemporal dementia and Alzheimer's. And for any rare disease, patients might see themselves reflected in a law in which lawmakers heard directly from patients about how limited research impacts their lives, and how they are able to live them.

"Everything we're doing here impacts our ability to do better for everyone suffering," said Laura Dalle Pazze, CEO of I AM ALS.

Rep. Mike Quigley, who sponsored the bill in the House, said that talking with colleagues, he often found others experienced similar losses. It felt like a uniquely bipartisan effort, he said. "We talk about working across the aisle. In this case, there was no aisle."

Quigley's father passed away from Parkinson's disease, the progressive nervous system disorder. He emphasized how little had been done in the years since ALS' namesake, Lou Gehrig, made his famous final speech.

"If I asked you to testify in Congress about all the progress we've made on ALS since Lou Gehrig said, 'I'm the luckiest man on the Earth,' the testimony wouldn't last long," Quigley said.

Now, he said, by expanding access to treatments, "You're giving people hope."

In testimony before the House of Representatives in July, Wallach tearfully explained in halting language, "I am 40 years old. I have been fighting ALS for four years."

Continuing on for him with a speech they wrote together, Abrevaya said, "I will be his voice." After telling legislators about their two daughters, aged 6 and 4, she said, "This is our closing argument for our lives."

This year, they are looking forward to more life.

After a tightened time during the beginning of the pandemic, the couple's two daughters are in school and hope to go to camp this summer. Wallach plans to attend their soccer games; he's the goalie, with wide wheelchair coverage, when they practice.

The decision to spend so much of whatever time Wallach has left fighting for others and a different future for him has never been an easy one. They have always been aware that every minute takes a minute away from somewhere else.

But this work has helped. They've secured funding for more research, including a 2019 grant from the Chan Zuckerberg Initiative to help patients, caregivers, doctors and scientists connect. In 2020, even as the pandemic limited their world—Wallach is extra vulnerable to the virus—they tried to turn world focus on vaccines and health research toward the fear of death their family feels daily, and a similar urgency toward treatments. This year, they also started a company, Synapticure, to help ALS patients with personalized care plans.

When they started I AM ALS, their goal was ambitious: $100 million of new funding within three years. And now, they note, they've matched that—and what the Ice Bucket Challenge raised in one social media viral moment—with annual funding.

After the Act for ALS passed, Wallach turned to Abrevaya.

He said, "See, aren't you glad I convinced you to do I AM ALS?"

She said, "Fine, you were right."

Recounting this, both laughed.