WHAT YOUR SUPPORT MEANS

ALS ASSOCIATION

ALS is devastating and it can strike anyone at any time, robbing them of their ability to walk, speak, eat, and eventually breathe. People living with ALS and their families come first. Our mission is to discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest. Translate that into simple terms, our goal is to make ALS livable, for everyone, everywhere, until we can cure it.

But it will take all of us—working together—to accomplish that goal.

It will take researchers and clinicians collaborating to find new treatments and cures. That means more clinical trials and patient participation in research. That includes finding ways to optimize treatments and care, increasing access to that care, and improving assistive technologies to help people with ALS live the way they want, with a better quality of life.

It also means we will need to prevent or delay the harms of ALS. We need to diagnose the disease sooner and find ways to identify ALS risk factors so we can prevent it altogether. And as new treatments are available, we need to fight for policies and access to allow people with ALS the chance to get the help they need sooner.

We optimize our mission investments to maximize impact for people living with ALS and their families. We are responsible stewards of our donors' dollars ensuring that we invest wisely in groundbreaking research, enhanced care, and infrastructure. Your generosity fuels this incredible progress, but to make ALS livable so much more needs to be done.

WHAT YOUR SUPPORT MEANS FOR OUR GLOBAL RESEARCH COLLABORATION

Recent advances in ALS treatments and assistive technology help to extend and enhance the lives of people living with ALS, and the researchers we support continue to bring new cutting-edge therapies to the patient community. The growing availability of better treatment options , which allows people to live longer with ALS, means the patient population will likely increase.

And the growing need will stress our current funding capability, so we must continue to grow financially to keep pace.

We need to keep pace for people like Larry Falivena.

In August 2017, Larry heard those three terrible words, “You have ALS.” Like most who experience the lengthy diagnosis process, Larry suspected that was the case. But actually, hearing it from his doctor was devastating. A husband and father of two young boys, he had so many plans for the future, or so he thought.

But after his diagnosis, Larry was encouraged to get a genetic test even though he had no known family history of ALS, and he says making that decision to move forward changed the course of his disease, and his life. Sure enough, a *SOD1* mutation was found, a known genetic cause for the disease.

Larry was able to get into an ongoing clinical trial for a treatment of SOD1-ALS called tofersen, now known as Qalsody. Thanks to donations that poured in from the Ice Bucket Challenge, we were able to invest in this ground-breaking treatment which has now been approved by the FDA to treat people with this form of ALS, people like Larry.

Your generous support will help us continue the critical work we are doing to discover new treatments and cures for this terrible disease, so one day, we can end ALS altogether.

> “I did participate in the Ice Bucket Challenge, and it was interesting because that was before I was diagnosed. And it’s just ironic that a few years later I was diagnosed with the disease and realized how important the Ice Bucket Challenge was.
>
> And now, 10 years later, I’m a beneficiary of all that money that was raised that spurred research and led to the treatment that I’m on now.”
>
> – Larry Falivena, living with ALS

WHAT YOUR SUPPORT MEANS FOR ALS CARE

To help make ALS livable for everyone, everywhere, we are working to ensure people living with ALS and their families have access to the care they need regardless of where they live. Our local care teams and teams of healthcare professionals across the country work tirelessly each day with one thing in mind—enhancing quality of life for people with ALS and supporting families impacted by the disease.

Access to multidisciplinary care has been proven to extend survival and improve quality of life, which is why it's critical we ensure people living with ALS can find multidisciplinary care close to them. Our work to expand our nationwide clinic network is very intentional, focusing on increasing access and utilization of this type of care. Using geo-mapping, we are trying to ensure people living with ALS and their families are near a clinic.

Expanding access to care is critical for people like Elizabeth Them.

Elizabeth, or "Biz" as she likes to be called, was born and raised in Ohio. Married now for 13 years, she has two wonderful stepdaughters, two dogs, and three alpacas. Yes, alpacas. After a trip to Peru, she thought they would be fun, but jokes they are "fun from afar," admitting they're really not that friendly.

A physical therapist by trade, she knew about ALS, and it was always in her periphery. At the age of just 30, she noticed she was having weakness in her hands; something as easy as buttoning a pair of pants was becoming a chore. She was officially diagnosed with ALS in 2017.

Biz and her family are fortunate to have access to one of our ALS Certified Centers of Excellence™ nearby. In just one appointment, she is able to see a team of specially trained health care professionals who can address the many needs of people living with ALS.

The care team typically includes a neurologist, physical therapist, occupational therapist, respiratory therapist, nurse, dietitian, speech language pathologist, social worker, mental health professional and an ALS Association liaison all working together to provide patients with the personalized care they when living with a complex disease like ALS.

"The staff at the Ohio Health ALS Clinic, they are just by far the nicest individuals, and they care about me as a person first, and then they are concerned about my ALS journey," she says.

We've expanded from 100 Certified Treatment Centers of Excellence™, Recognized Treatment Centers™ and affiliated clinics before the Challenge to 226 today, and more than tripled our network of multidisciplinary clinics from 33 before the Challenge to 97. But that's not nearly enough.

To truly make ALS livable, we need to ensure everyone diagnosed with the disease has access to multidisciplinary ALS care, like Biz. We need to provide the critical resources, programs, and services they need to live their lives with ALS the way THEY want to.

And that is only made possible by the generosity of our donors and supporters who are committed to helping people living with ALS.

> **"Being able to come here every three months and see every person I need saves me time, money. I mean, it makes it not only convenient, but enjoyable.**
>
> **I don't dread it. I don't love it, but I'm not dreading having another appointment. Coming here sitting in one room and they all come to me is the easiest for analysis. I mean, I hate saying it, but it all comes down to money. We need donations.**
>
> **I think you know more money for research and to provide services is key."**
>
> – Elizabeth "Biz" Them, living with ALS

WHAT YOUR SUPPORT MEANS FOR ALS ADVOCACY AND POLICY CHANGE

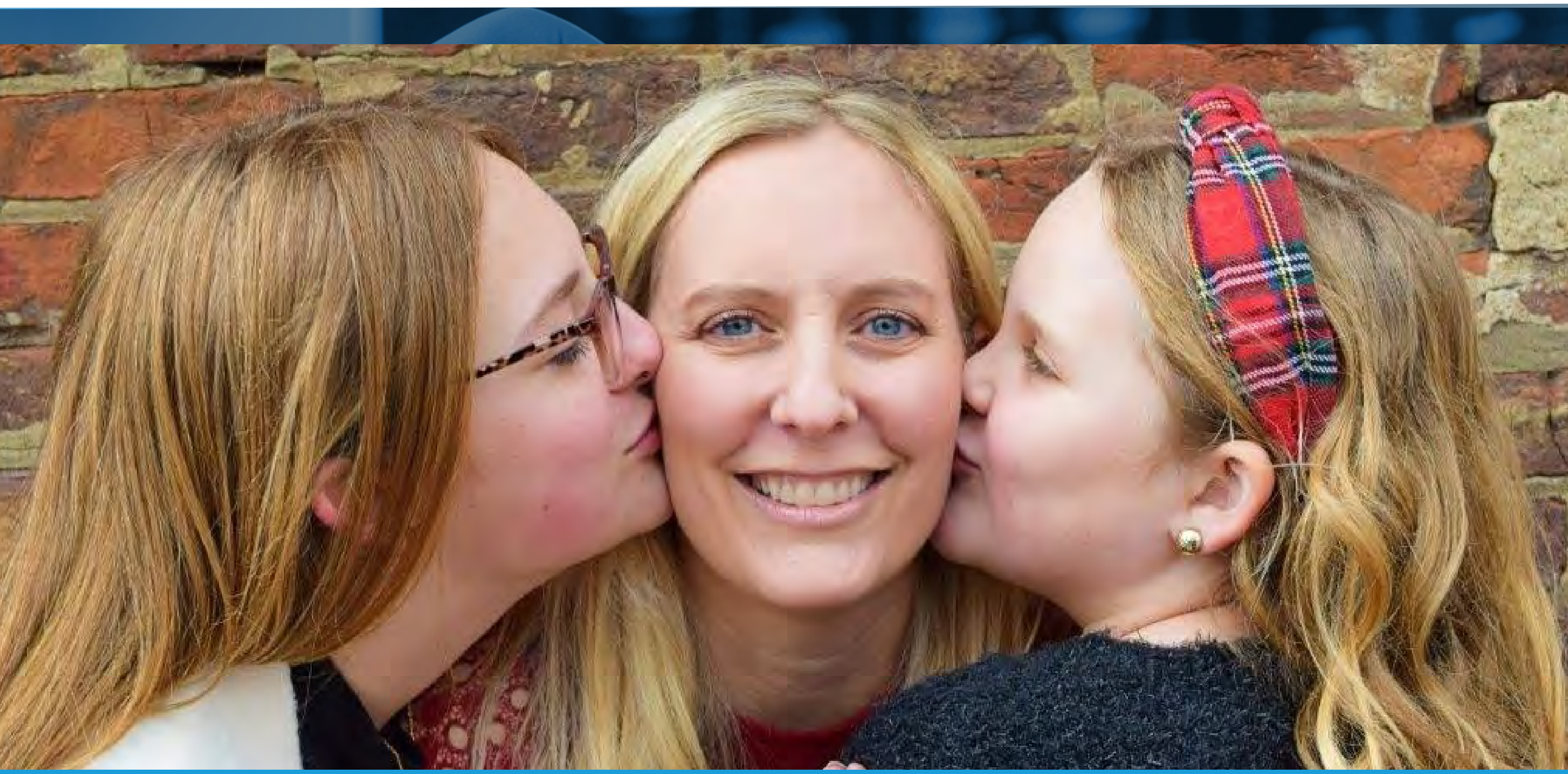
Each year, with the help of ALS advocates across the nation, we spend countless hours informing and lobbying members of Congress and state officials in all 50 states, urging them to support the critical needs of people living with ALS and their families and caregivers.

Our advocacy work focuses on educating and mobilizing all policymakers in a nonpartisan fashion to achieve our mission. To do this, we aggressively advocate for legislative priorities on national and state levels that will help to find new treatments and cures, optimize current treatments and care, and prevent or delay the harms of ALS.

But to continue this important work, we need the support of ALS advocates around the nation who are willing to amplify their voices and share personal experiences about the true impacts of ALS.

We need to continue this for people like Katie Adams.

Katie is a 39-year-old mother of two young girls, ages nine and fourteen. Prior to her diagnosis, she worked as an occupational therapist and rehab manager, so she knew early on how her symptoms that started in July of 2021 correlated with ALS. Logging and tracking her symptoms thoroughly, she set out on her journey to find the underlying cause of what was happening.



Like most people who are eventually diagnosed with ALS, she spent months visiting doctors and undergoing tests. Even with the extensive information she had collected about her symptoms, she continued to be dismissed from one doctor to the next. Finally, on October 28, 2022, she too heard those three awful words, "You have ALS."

While she admits she felt a sense of relief at first because she finally *knew* what she had suspected all along, she had no idea how real the fight ahead of her would become.

Katie's difficulties didn't end once she was diagnosed, they instead changed to other issues. She found out the hard way that because of a law in Kentucky, she did not have an option to purchase affordable Medigap insurance, the type of insurance needed to help cover the 20% Medicare does not cover.

She connected with her local ALS Association team about the issue and was offered the opportunity to share her story with legislators to try to help get the law changed to fix this problem for all people living in Kentucky. She testified in front of Kentucky's Health Senate Committee about her challenges, and why the law needed to be changed.

We're proud to report, after listening to her story, there was a unanimous "yes" vote on passing the new bill the new law in Kentucky took effect in January 2024!

> **"Have you ever heard the term 'the squeaky wheel gets the grease?' The ALS community needs to be a squeaky wheel and in order to do that we need more advocates: people living with ALS and people whose lives are affected by ALS."**
>
> – Katie Adams, living with ALS

But to make ALS a livable disease for everyone, everywhere until we can cure it, we need to see more funding to support ALS research and care.

With aggressive federal and state public priorities, and the help of ALS advocates and supporters like you around the nation, we will ensure the critical needs of families impacted by ALS are met.

The unmet needs in our ALS community will only continue to grow as the population begins to live longer due to an increased number of treatments, quality of life, and care. As new treatments for symptoms become available, the number of people requiring our assistance will rise. Your support can help us expand the critical programs and services we offer and grow the necessary resources to assist people living with ALS and their families, now and in the years to come.

Let’s see it end. Give today.

ALS ASSOCIATION