

I AM ALS

ANNUAL REPORT

2024



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Update from community teams

I AM ALS is a patient-led community that empowers volunteers to lead. We all believe that there is no better group of people to head up this movement than those who are impacted by it. Our community teams meet weekly to brainstorm, collaborate, and execute awareness events and initiatives to improve the quality of life for people living with ALS. Last year, we are proud that we achieved so much together. Here are some highlights:

- Our Tim Lowrey Panel Series reached close to 2,000 medical professionals in training through 28 presentations.
- The Lou Gehrig Day team hosted events that reached nearly 3,000 people at ballparks in major American cities through a partnership with Major League Baseball.
- The Clinical Trials team hosted webinars to provide valuable information and guidance to the newly diagnosed, and launched a new and improved patient-centric rating system for clinical trials.
- The Many Shades of ALS team focused on outreach to Black individuals impacted by ALS, who typically have to wait 12 months longer than their White counterparts to receive a confirmed ALS diagnosis.

Other projects included the Artistry of ALS; partnerships with affinity groups like one serving women under age 35 with ALS; resources to address issues of misdiagnosis and delayed diagnosis—like Could it Be ALS; and rolling out Empathy Dinners. Special shout-out to our Thank You Squad, who sends out handwritten notes to every single person who donates to I AM ALS!

We look forward to many more successes as we increase awareness of and continue seeking a cure for ALS.

Learn more about I AM ALS community team leaders and see the full squad of our team leaders [here](#)!



I AM ALS Community Teams

- **Veterans**
- **Many Shades of ALS**
- **Community Outreach**
- **Legislative Affairs**
- **Clinical Trials**
- **Thank You Squad**
- **Fundraising**
- **Lou Gehrig Day**
- **Scribes of Strength**
- **Team Up for ALS**

I AM ALS

History

Our Founding

I AM ALS was founded in 2019 by Brian Wallach and Sandra Abrevaya after Brian was diagnosed with ALS at the age of 37. Determined to expand resources for research and find a cure for ALS as quickly as possible, Brian and Sandra tapped into their political and community organizing background, building what is now the largest patient advocacy movement of the 21st century. By working with the ALS community and harnessing their collective power, we are relentless in our goal to end ALS.



Our People



“What have I gained by becoming a ‘serial volunteer’ with I AM ALS? The chance to drive change and be part of a dynamic community dedicated to helping people who are living with ALS and their families... And ultimately finding a cure for this disease.”

*-Tim Abeska, I AM ALS volunteer
with wife Mary Ann at left
who died of ALS in 2019*

More History

Our Community Wins

Our superpower is our people: people living with, impacted by, and highly motivated to end ALS. I AM ALS is fueled by urgency to find a cure and has a track record of real impact:

- For decades, federal funding for ALS research was flat, with just \$57 million allocated annually—until I AM ALS was born. In six years, we’ve become a multiplier and disrupter, driving \$1+ billion for ALS by harnessing the grit, urgency, and energy of the ALS patient-led community movement.

Scan or click to watch the trailer of “For Love & Life: No Ordinary Campaign”!

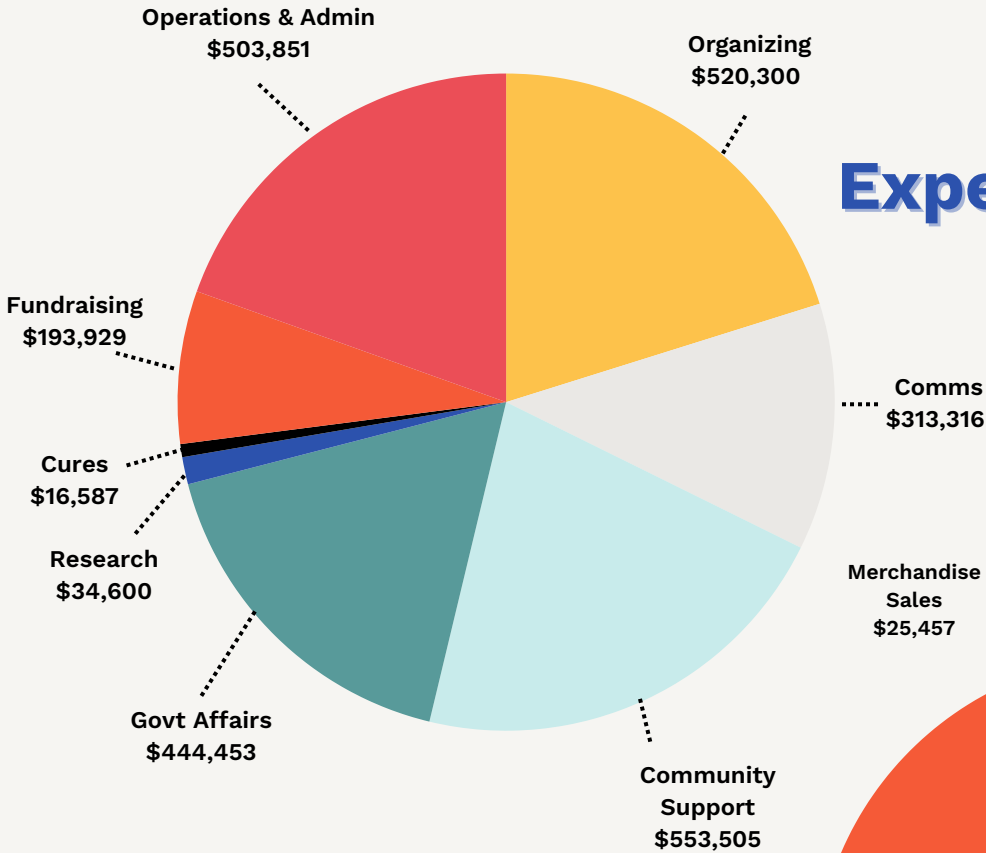


- Driven into law by I AM ALS, the 2021 ACT for ALS unlocked dollars for expanded access programs (EAPs), giving patients access to otherwise inaccessible promising treatments and trials. To date, five EAPs have created 690 patient treatment pathways, while expanding research on biomarkers and drug delivery mechanisms.
- Our community has repeatedly and successfully educated the FDA about the importance of flexibility and speed in therapy approval, giving the community faster access to multiple experimental treatments.
- The I AM ALS community understands the urgency of ALS. By empowering and organizing our advocates, we’ve been the conduit for more than 300,000 actions—including letters to policymakers, story-sharing, and community-led events.
- I AM ALS has provided expert support to more than 3,400 patients and caregivers, connecting those with similar experiences to share information, services, and programs.

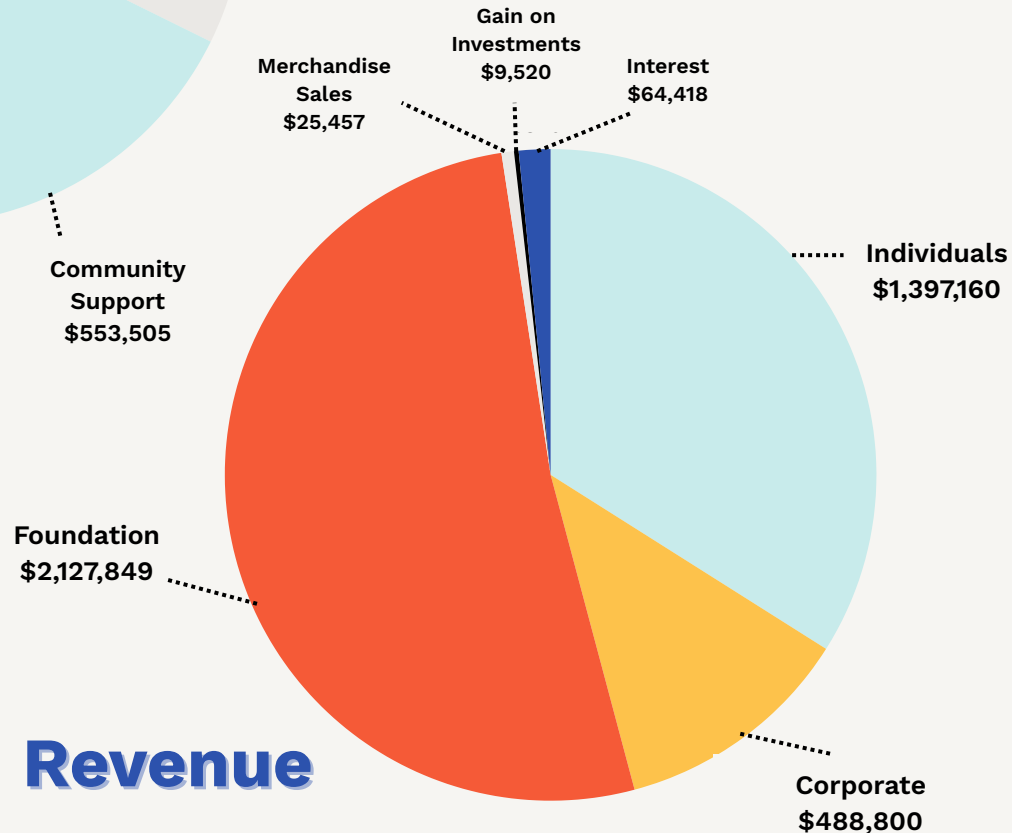
2024 Financials

The figures here are not considered final until the completion of the 2024 annual audit.

Expenses



Revenue



Our Generous Donors

We'd like to extend a huge thank you to our supporters who gave \$100,000 or more in 2024:

*Mackenzie Scott Yield Giving Open Call Fund
Guaranteed Rate Foundation
The Hummingbird Fund*

And those who gave \$25,000 or more:

- *Dilworth Paxson LLP*
- *Robert's Ride for Doug's Drive*
- *Groove Subaru*
- *Gateway Triangle Corp.*
- *Original Terlingua*
- *International Chili Cook-Off (OTICCC)*
- *Inistro, Inc.*
- *Knight Foundation*
- *James Godwin*
- *Risk and Benefits FSA*
- *Samantha and Scott Zinober*
- *Anonymous board member*
- *Rosenthal & Rosenthal*
- *Mitsubishi Tanabe Pharma America*
- *Ben and Shannon Sloop*

I AM ALS

COMMUNITY TEAMS



CLINICAL TRIAL TEAM
CO-LEADS
DIANE HOEY
DAN MCINTYRE
BOB HEBRON



VETERAN TEAM
CO-LEADS
LARA GAREY
TIM ABESKA



LOU GEHRIG DAY TEAM
CO-LEADS
PETE SPENCER
KASSIE STEPHENSON



LEGISLATIVE TEAM
CO-LEADS
GARRETT MAY
JACK SILVA
TROY FIELDS



YOUTH LGD TEAM
CO-LEADS
BRIAN ANDREA
GINGER HANCOCK
SUE HILLER



COMMUNITY OUTREACH
TEAM
CO-LEADS
JULIET TAYLOR
TIM ABESKA



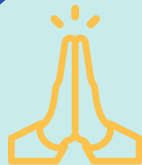
MANY SHADES TEAM
CO-LEADS
KENDRA WOMACK
RANDY GREGORY



SCRIBES OF STRENGTH
TEAM CO-LEADS
ELIN ADOCK
STEVE LYONS
EMILY CERBONE



PPA SUBGROUP
CO-LEADS
SARA BURKHART
TROY FIELDS



THANK YOU SQUAD
CO-LEADS
GIA POLO
KATIE KIRKPATRICK



TEAM UP FOR ALS
CO-LEADS
RANDY GREGORY
MATT ROCHELEAU



COMMUNITY
FUNDRAISING CO-LEADS
JAKE WENTWORTH
KATIE BROWNLEE



A Win for Our Veterans

Thanks to tremendous collaborative advocacy work in 2024, I AM ALS and a coalition of Veteran Service Organizations (VSOs) helped pass the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act.

Led by our partners at the Elizabeth Dole Foundation and Paralyzed Veterans of America (PVA), and thanks to 1,800 ALS advocates writing their legislators, this bipartisan bill was signed just after the new year, on Jan. 2, 2025.

The law provides critical resources and support for veterans living with ALS and their families. Importantly, the bill halts the separation of Veterans living with ALS from their caregivers and loved ones. Veterans can now continue to receive care in their home and no longer face a price cap that forces them out of their homes and into institutional care, sometimes hours from their homes and support networks.

**Support surviving
spouses of ALS
Veterans by telling
Congress to
cosponsor the
Justice for ALS
Veterans Act!**



*Scan or
click to
visit our
Online
Resource
Center!*



Supporting Our Community

In 2024, I AM ALS' community support programs provided care and support to more than 1,000 people through our concierge-style support program, our one-of-a-kind peer mentor program, and weekly support groups.

The community support team also launched two new programs: the ALS Comedy Crew, a new program to process the ALS experience through humor; and a peer support specialist program, leaning into our superpower once again to train community members impacted by ALS on how to help others navigate the disease.



Highlighting Our Caregivers



Emma Terry, age 22, is a dedicated I AM ALS volunteer and celebrated beauty queen with a mission: she wants to raise awareness of ALS and eventually find a cure for the disease. Born and raised in Leads, Alabama (a suburb of Birmingham), Emma's whole life has been marked by ALS: her grandfather Stewart Simpson had a slow-progressing type of ALS, also known as Lou Gehrig's disease. He lived with ALS for 22 years before he died in 2024 at the age of 86.

"I grew up watching him decline," Emma says. "His case was different than most—because he was progressing slower, we had more time. But it took his voice right away. I never heard him speak." Emma lived close to her grandparents, so she served as one of his caregivers as she was growing up, alongside her mother. As a caregiver to her grandfather, Emma learned resilience and to seek out joy in every day, even despite the challenges.

"It took me a long time to realize that this wasn't normal—that not every kid helped take care of their grandparent," she says. "I know it's easy to feel alone in these struggles. It's important to find ways to share your story so you can know you're not alone." After her grandfather's death, Emma found I AM ALS and now volunteers on the legislative team.

"Being a volunteer for I AM ALS pushes me to be a better advocate and to continue to share my story even on the days that it's hard," Emma says. "It's been life-changing."

"This is a community of people that are going through the things I was going through. It opens up so many doors. When you realize that there are other people facing the same struggles, you feel less alone. To have this community of people who are like family... They give you motivation to keep going." Emma will be competing in the Miss America Organization competitions as Miss Hoover 2025. She's also a full-time college student studying accounting.

I AM ALS Outreach Efforts

Tim Lowrey Panel Series

There are some things you can't learn from a lecture or textbook. This is why the I AM ALS Community Outreach team developed the Tim Lowrey ALS Panel Series (TLPS), bringing a virtual panel discussion on ALS to medical students, associations, organizations, clubs, and more.

TLPS is named after panelist and advocate Tim Lowrey, a former pharmacist living with ALS. Tim began the series to educate more people about ALS at their school or workplace. Fun fact: The first panel was hosted for pharmacists at Wegmans, where Tim used to work.

In 2024, I AM ALS' Community Outreach team educated 1,778 medical professionals and students about ALS and how to better serve people living with ALS and their caregivers through this series.

Request your own panel for your workplace, class, or organization by scanning the QR code on this page or [click here](#).



Lou Gehrig Library Campaign

In 2024, I AM ALS launched a creative new national ALS awareness campaign with libraries nationwide. Across the U.S., libraries displayed information on ALS and Lou Gehrig, alongside books about ALS and prominent individuals with ALS. Even the Library of Congress joined the movement to end ALS!

By the Numbers

1,778 Medical Professionals Reached



**34 Libraries Across the U.S.
with 1,800 Participants**



A Year of Action

I AM ALS is the only organization made up of the very people living with, impacted by, and highly motivated to end ALS. Our community of incredible volunteers created so many opportunities for awareness and action in 2024. They hosted Lou Gehrig Day events, advocacy trainings, educational sessions, congressional hearings, and even an art exhibit. This advocacy and awareness work drove 16,000 online actions via our website.

In addition to thousands of actions taken, our patient-led advocacy engine joined with 20 ALS community organizations to secure \$258 million in federal funding for ALS in 2024.

Building and sustaining this movement has been fueled by our urgency to find a cure. Thanks to our community, we have a track record of real impact, including:

- Steep increases in research funding to get closer to treatments and cures. After federal funding for ALS research had been flat for decades—at just \$57 million annually for research grants. I AM ALS pulls the biggest lever possible and advocates for increased federal dollars. We've now realized \$1+ billion for ALS in just six short years by harnessing the grit, urgency, and energy of the ALS community movement.
- Immediate access to therapies. To date, five EAPs have created 690 patient treatment pathways, while expanding research on biomarkers and drug delivery mechanisms.
- Conveying urgency to federal agencies. By educating the FDA about the importance of flexibility and speed in therapy approval, the community has a chance to access experimental treatments without delay.
- Hope through connection and purpose. We continue to offer expert support to thousands of patients and caregivers, connecting those with similar experiences and providing people with the information, services, and programs they need.

ALS Landscape

When founded in 2019, I AM ALS joined with other ALS organizations to accelerate impact and increase collaboration.

**Before I AM ALS
was created in 2019**

**Research
grants**

**Patient
Engagement**

**Policy
Advocacy**

**Federal
Investment
in ALS
Research**

**Equipment
& Financial
Aid**

**Support
services**

**After I AM ALS
joined the landscape**

**Patient and
Caregiver
Movement***

**Equipment &
Financial
Aid**

**Policy
Advocacy***

**Awareness &
Visibility of
ALS
Experience***

**Support
services***

**Peer
Support***

**Research
Grants**

**Federal
Investment
in ALS
Research***

** Indicates I AM ALS Impacted Area*



First Ever ALS Community Summit

I AM ALS hosted the first ever ALS Community Summit in May 2024. The event included an awards ceremony, collaboration with more than a dozen ALS organizations, six panels representing experts sharing best practices in care, advocacy, and more, as well as our fourth annual display of 6,000 blue flags on the National Mall. During this annual event we honor all of those living with and lost to ALS and raise awareness of ALS in Washington, DC.

Total Registrants

Community members who registered for the Community Summit.

439

400

In-Person Attendees

Community members who attended the Community Summit in person.

Virtual Attendees

Community members who attended Summit panels virtually.

87

65

Legislative Advocates

Total community members who participated in legislative meetings with 41 members of Congress.





Convening the Neuro Community

In April 2024, I AM ALS launched the Cures Collective, a novel and much-needed ALS and neurodegenerative disease (ND) coalition. Cures Collective is focused on uniting advocates and organizations that are committed to ending neurodegenerative diseases to unlock critical breakthroughs across the field.

While there are convening efforts focused on neurology, there is currently no comprehensive, coordinated awareness initiative across neurodegenerative diseases. Few forums exist that bring together key stakeholders—such as researchers, clinicians, patients, and policymakers—for meaningful discussion.

More collaboration and visibility leads to progress in public understanding, care practices, federal resources, and supportive policies for those affected. That's why I AM ALS is powering the Cures Collective. Who we are and what we do:

- Steering committee: I AM ALS, PD Avengers, Hummingbird Fund, Les Turner ALS Foundation, Hop on a Cure, with advocates Jenny Fortner & Dr. Jinsy Andrews
- Now more than 50 member advocates & organizations representing ALS, Parkinson's, FTD, Alzheimer's, Huntington's, MS and cross-neuro/brain health.
- Cures Collective has working groups focused on public awareness, patient and caregiver support, policy, and the research ecosystem.

***1 in 4 people are likely
to be diagnosed with a
neurodegenerative disease.***



Members of the Cures Collective

More Than Therapy: EAPs Offer Hope

In the remote coastal community of Seldovia, Alaska, Vivian Rojas is a retired teacher living with ALS. Her home is only accessible by boat or by plane, so access to medical care can be an arduous task. After she was diagnosed in 2018, Vivian wondered if she'd be able to access the medical care she'd need to manage the neurodegenerative disease.

“Opportunities to get access to treatments and therapies for someone in a remote area like myself are harder to find,” she says.

Now, thanks to the 2021 law Accelerating Access to therapies for ALS (ACT for ALS), Vivian is participating in an Expanded Access Program (EAP), which functions similarly to a clinical trial and is offered by CLENE Nanomedicine. In addition to treating her symptoms and slowing the disease progression, the EAP “is giving me hope and purpose to find a cure, so that I have more time to share my story.”

“The opportunity to be a participant in the EAP gives me optimism that we can win this fight and find a cure, as long as we are given a chance,” Vivian says. After her diagnosis, Vivian began working with her neurologist to learn about more resources and trials available to her and others living with the disease. She learned about the CLENE program several years later through Synapticure, a company founded by I AM ALS co-founders Brian Wallach and Sandra Abrevaya.

Vivian continues to live on her own for now, though she knows that is not always going to be possible. She also passes the long, dark winter months in Washington state, living with her daughter and family, where she spends time with her 3-year-old grandchild and other family members who live close by. Vivian considers herself fortunate.



*Vivian
(center, with
a child on her
lap) with her family*

(cont'd on pg. 18)

More Than Therapy: EAPs Offer Hope

(cont'd from pg. 17)

“As long as we have these EAPs, we’re doing something that can make a difference for people living with ALS now or maybe for the next generation,” Vivian says. “These programs are giving hope to people who don’t have much hope otherwise.”

The ACT for ALS is up for reauthorization by Congress in 2026. Learn more about the recent developments and news [here](#).

ACT for ALS Expanded Access Programs

ACT for ALS, which stands for Accelerating Access to Critical Therapies for ALS, was passed into law in late 2021, thanks to the patient and community-led advocacy work organized by I AM ALS. When it was signed into law, ACT for ALS established the following:

- An expanded access grant program that not only funds research on promising investigational treatments, but also provides access to them to people living with ALS who are not eligible for clinical trials.
- A public-private partnership that includes three closely integrated components: the Critical Path for Rare Neurodegenerative Diseases (CP-RND), announced in 2022; the Access for All in ALS (ALL ALS) Clinical Research Consortium; and the Accelerating Medicines Partnership® for Amyotrophic Lateral Sclerosis (AMP® ALS).
- The goal of AMP® ALS is to accelerate the development of effective ALS treatments and biomarkers for the disease. AMP® ALS is bringing together data and biospecimens from many different studies, including ACT for ALS expanded access programs, the ALL ALS consortium, and more.
- ALL ALS is operationalizing the research objectives of AMP® ALS by enrolling 2,000 people as part of a large-scale natural history study.

Patients are getting access to therapies now because of the ACT for ALS. Learn more about ACT for ALS and reauthorization as an advocacy priority in 2026 by scanning the QR code or clicking [here](#).



A Letter from our Board Chair

Dear I AM ALS Community,

As I reflect on 2024 and my first year as the chairperson of the board of directors, I feel immense gratitude for this incredible community. It is you—our advocates, volunteers, partners, and donors—who give us strength and perseverance as we celebrate our sixth year in action. Our superpower is our people: I AM ALS is the only national community movement made up of those who are closest to, deeply impacted by, and capable of ending ALS. That's what makes us different; that's what makes us great—people like YOU.

When I lost my dad to ALS almost 18 years ago, I never imagined being a part of such a powerful and compassionate movement. It's been incredibly rewarding to serve as a board member over the past six years and humbling to step in as chairperson this year.

This report contains much more than data and statistics about the last year—it is a statement of hope through connection and action. In 2024, we connected with hundreds of people recently impacted by ALS; supported them and their loved ones; shared beautiful and painful caregiver stories; and advocated for legislation to protect Veteran families with ALS. We saw more incredible impact of ACT for ALS in hundreds of new EAP treatment pathways; convened a neurodegenerative disease collaborative; and launched a peer support specialist program. And we're just getting started.

The future of I AM ALS is strong, thanks to you—our community of advocates and changemakers. I look forward to seeing what you all do next.

In advocacy,



Peter Bowen

I AM ALS Board Chair



*Thank
You!*

We're grateful to support this
amazing patient-led community!



The team at I AM ALS
Pictured here at a 2024 staff retreat