



IAM ALS

Impact Report

— 2023 —

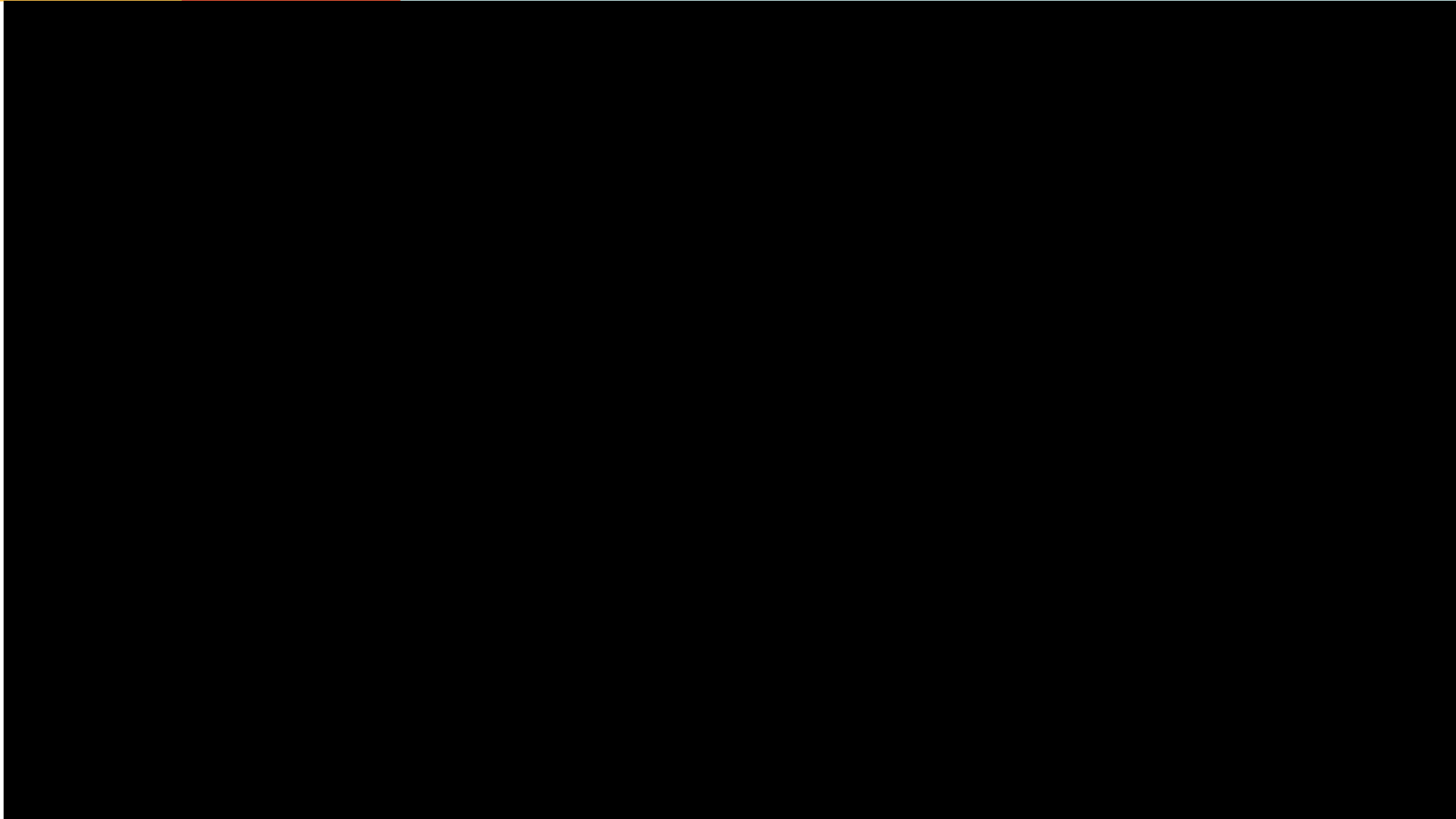


The Faces of ALS





Welcome to I AM ALS



WATCH HERE





Since Wallach's ALS diagnosis in 2017, the couple has spearheaded *arguably the most successful patient advocacy campaign this century.*

— **STAT News**

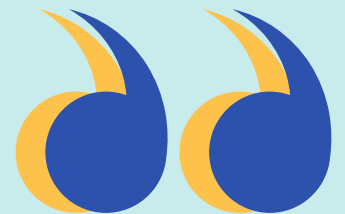


Table of Contents:

<i>About I AM ALS</i>	1
<i>What is ALS?</i>	2
<i>Co-Founders Message</i>	3
<i>History in the Making</i>	4
<i>I AM ALS Return on Investment</i>	5
<i>I AM ALS Impact</i>	6-11
<i>The Future of ALS</i>	12-13
<i>I AM ALS Financials</i>	14
<i>Media Coverage</i>	15
<i>Partnering to End ALS</i>	16
<i>Leadership</i>	17
<i>Ending ALS Together</i>	18

About I AM ALS:

I AM ALS (IAA) is a patient-led community that provides critical support and resources to those living with ALS, their caregivers and loved ones. Founded in 2019 by Brian Wallach, living with ALS, and Sandra Abrevaya, his wife, IAA is revolutionizing how we cure ALS by empowering and mobilizing advocates to raise mainstream awareness as well as lead the revolution against ALS in driving the development of cures by engaging with policy-makers.



IAA was created for people living with ALS, by people living with ALS. Why is this such a big deal? Because our efforts to find a cure for ALS will be more effectively led by those who are most affected by the disease. When we alter that reality, not only are we better able to assist patients, but we are also compelled to work within the constraints of the ALS clock and hasten our search for treatments. IAA will keep being propelled by the voices of patients to fight for change we demand – until ALS is eradicated — through advocating, empowering, educating, and amplifying progress.

The question is no longer IF we will find cures for ALS, but when. That answer depends on all of us.

What is ALS?

Amyotrophic lateral sclerosis (ALS) is a disease of the nervous system, affecting nerve cells in the brain and spinal cord. ALS causes muscular weakness that worsens over time and eventually affects the ability to move, speak, eat, and breathe.

U.S. military veterans are 2-10x as likely to develop ALS.

While ALS can affect anyone, at any age, some are more at risk than others. Rates of ALS are significantly higher among veterans, and the VA has designated ALS as a 100% service-connected disease.

ALS can affect anyone, at any time.

1 in 300 people will be diagnosed with ALS in their lifetime. 90% of those diagnosed have no family history of ALS, and there are currently no cures. I AM ALS is here to change that.



I AM ALS 'Every Community'
Map of ALS Impact

ALS is always fatal.

People typically live for 2 to 5 years after diagnosis. While some may progress slowly and live for many years after diagnosis, ALS will eventually claim the life of every person diagnosed.



Brian Wallach & Sandra Abrevaya, Co-Founders, I AM ALS

"You have a condition that has been around for 160 years, and everyone reminds you that there is absolutely nothing that can be done about it. Because it is too complicated, and it will take time to find a cure. Then you say thank you, and while making eye contact with them, say, "I'm going to prove you wrong.""

My wife was opposed to the idea of establishing an ALS advocacy nonprofit when I initially broached the subject, after receiving my ALS diagnosis. Today, I'm relieved that I persuaded her otherwise.

That was in 2019, and now, almost five years later, we have galvanized what is likely to be the greatest successful patient advocacy movement of the 21st century. Even if we have not yet found a cure for ALS, we have formed a movement that resulted in President Joe Biden signing legislation to finance \$600 million of ALS research and patient-focused initiatives over the next six years. This is a significant step forward in the fight against ALS. We leaned on a network that includes top Biden aides, the creators of "Pod Save America," legislators, the White House press secretary, a famous Peloton instructor, and former President Barack Obama himself, and we used it to steer never before seen sums of public money toward a long-neglected disease diagnosed in just 5,000 Americans each year.

To the patients, caregivers, advocates, donors and all supporters of I AM ALS, thank you for fighting with us. I am filled with optimism because I am certain that a cure for ALS will be found within my lifetime and that I will live to raise my daughters with my wife and live to do the father-daughter dance at my daughter's wedding. Thousands of people's lives will be altered positively because of this cure, and no one will ever again have to hear the words "you have ALS, get your affairs in order."

When we prevail, we will have unlocked crucial innovations that will be used to end neurodegenerative diseases such as Parkinson's, Alzheimer's, frontotemporal dementia, and more. By eliminating these illnesses, we will have prevented the deaths of an estimated 135 million individuals.

At I AM ALS, this is our greatest hope. A cure will be found. That's the fact.
The dream is doing it in the next three years, not in 20 years.

I AM ALS accelerates progress through three primary pillars of impact:



We are patient-driven. We have incredibly passionate volunteers who organize. These, in themselves, are not entirely novel. The revolution began when I AM ALS provided our patient-driven community of passionate volunteers the platform to mobilize and empowered their organizing capability to advocate for change.



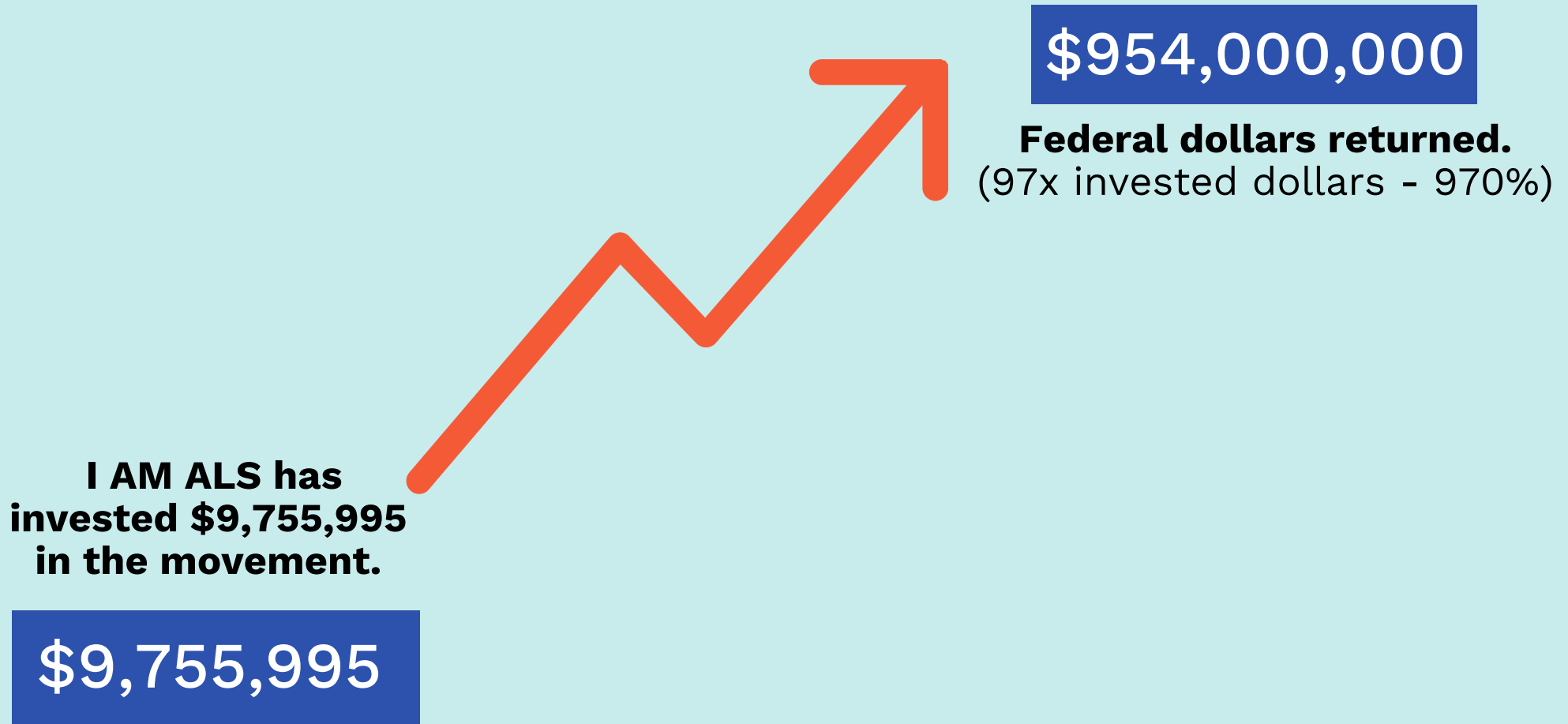
The Words of Sandy Morris

"The power of the patient is huge. It's actually putting action items and next steps, and passion behind that, and really an accelerated feel to get this done, and it's working."

**To DONATE
To ACT**

I AM ALS Return on Investment

I AM ALS has received generous support that enabled an unprecedented, almost 100x return on investment through federal dollars realized for ALS research and patient treatment access.



I AM ALS Impact

**Launched
in
2019**



**Ended
ALS disability
insurance
waiting period**



**Secured
\$954 million
in federal
research
funding**



**Approval of 3
new ALS
treatments**

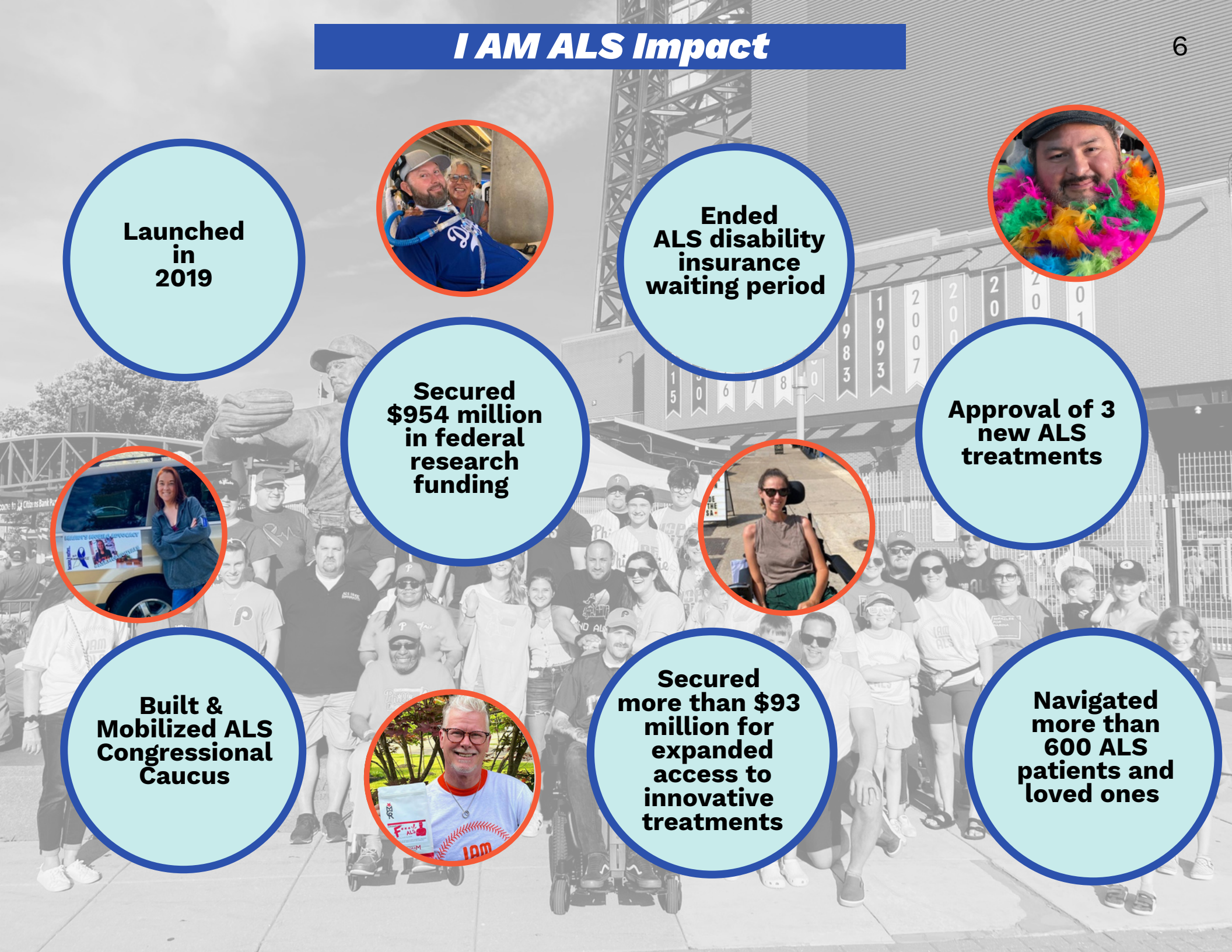


**Built &
Mobilized ALS
Congressional
Caucus**



**Secured
more than \$93
million for
expanded
access to
innovative
treatments**

**Navigated
more than
600 ALS
patients and
loved ones**



With your help, we've accomplished so much since 2019!

2019:



I AM ALS is created



Launched community teams

Took over Times Square



Conducted a community needs assessment



I AM Juliet Taylor

“I can't turn my back on ALS until we all can. That's why I am here, and proud to fight alongside all of us until we can get rid of this thief of a disease once and for all.”

**To DONATE
To ACT**

Five Years of Impact...

2020:



Doubled ALS research funding at DOD + helped create a new NIH ALS research program



Launched the Online Resource Center; Peer Support Initiative; ALS Signal for navigating trials; the Patient-Centric Trial Design (PaCTD) rating system; and the ALS Support Team - serving nearly 150 people

Passed the ALS Disability Insurance Access Act to end the five-month waiting period



Led petition with over 43,000 signatures to speed up access to AMX0035 (Relyvrio)



Launched the Tim Lowery ALS Panel Series to educate medical professionals and students



Sponsored and facilitated ALS advocate presenters at the International Symposium on ALS/MND



I AM Juan Reyes

“Why do I fight? I fight for myself, my family, my friends and for everyone living with ALS. And we are not alone. I AM ALS, an organization established by patients and passionate ALS champions, has quickly gained momentum, creating a tsunami of activity unheard of in the ALS community.”

**To DONATE
To ACT**

Five Years of Impact

2021:



Launched an Outreach & Inclusion Initiative to address disparities and the Organizing Playbook, a community mobilization tool



Hosted ALS community listening sessions and subsequently launched Many Shades of ALS team and the Familial ALS team



Delivered a petition with over 50,000 signatures urging FDA to make AMX0035 available to people with ALS

Passed the Accelerating Access to Critical Therapies Act (ACT for ALS)



Hosted 22 Lou Gehrig Day baseball meetups with 2,000 participants



Initiated 55,800 emails and drove 45,900 actions, taken by 31,927 advocates, for a total of more than 200,000 advocate actions



Developed a social media campaign and resources to help Veterans living with ALS address suicidal ideation and planning



I AM Jim Plews-Ogan

“I work with IAA because we get things done, we make a difference, and we inspire and support one another on the ALS journey. Join us. We need you, and you might find that you need us too.”

**To DONATE
To ACT**

2022:

Five Years of Impact



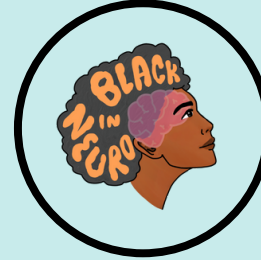
Secured \$25 million for FY22 and \$80 million for FY2023 ACT for ALS (\$75 million for EAP)



Provided 1:1 support to >550 people impacted by ALS, trained 100 new mentors and mentees, and hosted 72 support groups



Hosted inaugural ALS Awareness flag event in DC with almost 800 attendees



Collaborated with Black in Neuro to host two programs, NeuroRacism and Where Research Meets Reality



Organized and delivered a petition to FDA with over 30,000 signatures to the FDA supported by 20 ALS organizations requesting an Advisory Committee meeting (AdComm) for NurOwn

Launched the Ask Me Anything ALS Series

Hosted over 100 events with more than 7,000 participants

Offered vital information to 50,000 people through the Online Resource Center

Brought together key opinion leaders for the clinical trial Action Summit

Hosted Hispanic Heritage Month events with ALS Association Golden West Chapter and created a Spanish-language resource page

Led a community letter to Congress advocating for funding for strategic ALS programs including the continued implementation of ACT for ALS

Submitted comments for the NINDS ALS Action plan

Let's Talk About It
A mental health series



WORTH SAVING



NIH
NINDS



I AM Merit Cudkowicz

"I remember the first day someone told me, "You have to meet this guy [Brian Wallach], he's gonna change the world of ALS." And, he did."

To DONATE
To ACT



Led community Town Hall for Tofersen (Qalsody) and advocated for approval



Continued leading the demand for access to Relyvrio for Veterans living with ALS



Submitted almost 100 funding requests to Congress to fully fund ACT for ALS and increase CDMRP ALS research



Take Action

295,000+ actions taken to end ALS through the website since 2019



47,000+ I AM ALS email subscribers and 51,000 social media followers across 5 platforms



30,000+ accessed critical information and tools through the Online Resource Center

Spearheaded community letter to Congress advocating for FY24 funding priorities



Demanded the NurOwn Advisory Committee meeting and fair review



Submitted testimony to Senate and House Appropriations committees advocating for ALS community funding priorities



160+ incredible advocates contributing weekly across nine community teams



Served 194 new people impacted by ALS through the ALS Support Team, connected 38 people with trained ALS mentors, and hosted 56 support groups



I AM Kristin Rankin

“The IAA staff and volunteers have been so welcoming and encouraging -- they make it easy to get involved in whatever capacity you can... Most importantly, the people I've met through IAA inspire me to keep fighting this awful disease with their commitment to and love for the community.”

To DONATE
To ACT

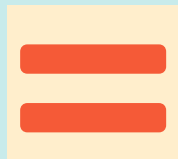
What Will the Future Bring?

This community has made enormous strides.
Now is the time to build on this impact.

Over the next five years, our fervent focus will be on the following:



Solving institutional approval and access challenges



Continuing to address disparity for those experiencing racial, rural, and income barriers



Growing support and access for veterans



Getting more therapies in bodies



Engaging and sustaining a strong community



Building a larger cross-condition movement

To Act:



To Donate:

I AM ALS is at a pivotal moment to expand our message and unify with the broader neurodegenerative community to ask for **#curesforall**.

This initiative will bring together a coalition to focus on:



Co-creating awareness campaigns with advocate voices from MS, Frontotemporal disorders (FTD), Parkinson's, and Alzheimer's

Explaining to the world that research advances in any of these diseases bring answers to the others



Unifying in legislative or policy actions where a broader coalition brings more change and attention

Building an egoless and collaborative research ecosystem where sharing is encouraged, with a goal of urgency



Broadening the community to new and diverse perspectives, voices, and communities

Together, we will identify treatments and cures and build a sustainable community for hope.

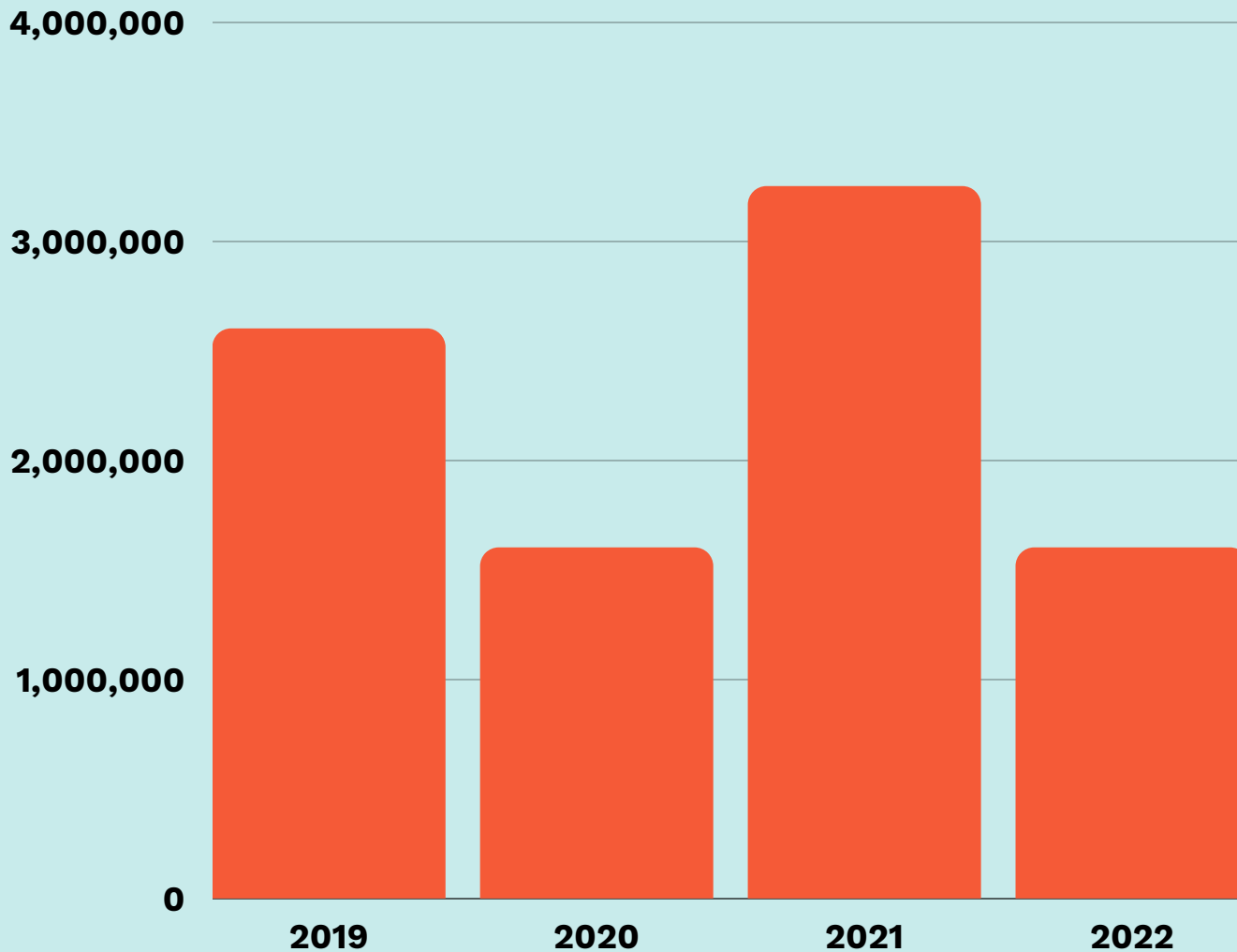


table 1. revenue by operating year

As a virtual organization with volunteers leading the movement, I AM ALS has kept costs low & impact high.

Expenses focus on staffing and basic infrastructure (i.e. technology, accounting, etc.) needed to accomplish our core pillars of community organizing, support, and policy action.

We've started a national conversation about ALS to educate and inspire new advocates to join the movement:



[Race to a Cure for ALS](#)



[New Father's ALS Fight Inspires Others With Hope](#)



[Former Obama Staffer Seeks ALS Cure](#)



[He Was Given 6 Months to Live. Then He Changed D.C.](#)



[A Race to Rethink Care After a Dire Diagnosis](#)



[FDA approves first ALS drug in 5 years after pleas from patients](#)



[Former Obama Staffer Fights to Raise ALS Awareness After Devastating Diagnosis](#)

and MORE....

[Stat News: I'm going to prove you wrong: How a D.C. power couple used an ALS diagnosis to create a political juggernaut](#)

[Chicago Today, NBC Chicago: Katie Couric, Phil Rosenthal Get Behind Extraordinary Documentary 'No Ordinary Campaign' to Raise Awareness for ALS](#)

[Chicago Sun Times: 3 Local Chicago Film Festival Docs Tell Local Stories](#)

[WIRED: My Friend Was Struck by ALS. To Fight Back, He Built a Movement](#)

Plus, our very own feature film: [NO ORDINARY CAMPAIGN](#)



We will not end ALS on our own, which is why collaboration is crucial. This new paradigm allows us to rethink and reinvent not just how we will end ALS, but every rare illness when we bring more actors into this movement. We are stronger when we fight together across diseases and organizations. We would not have been able to accomplish all of our success without the incredible help of our partners like the Chan Zuckerberg Initiative, former President Barack Obama, and others.

We extend heartfelt thanks to the following supporters of \$100,000 or more for their generosity over the years:

**Chan Zuckerberg Initiative
Crankstart Giving Fund/San Francisco Foundation
Joe and Carson Gleberman
Anas and Staci Iqbal
Eric and Liz Lefkofsky
Meadowlark Media Inc.**

**Richard H. and Cynthia P. Morehead
Poarch Band of Creek Indians
Phil and Monica Rosenthal
The Steven H. Madden Foundation
Tambourine Foundation
Steuart Walton**

As well as the following supporters of \$25,000 or more:

**Adira Foundation
Connie Ballmer
Joshua and Anita Bekenstein
Roger and Martha Bland
Judy and Peter Blum
Kovler Foundation
Peter Bowen
David and Katherine Bradley**

**Estate of Robert Duncan Brown III
Edwin Cohen
Google Ventures
Gray Foundation
Matthew and Alice Hehman
Alberto Ibarгүйen
The Klei Family Charitable Fund
Knight Foundation**

**David and Laura Krane
Jeff McNatt
Scott Muller
Mary Obelnicki
Neel Parekh
Todd Park
Alice and Ben Reiter
Peter Richards**

**Silicon Valley Community
Foundation
Southern Motion, Inc.
Graham Spencer
Margie and Nate Thorne
Daniel Tate, Jr.
Ruth Tate
Beth Zimerbort**

And to our in-kind support partners:

Forbes Tate Partners

Skadden, Arps, Slate, Meagher & Flom LLP

Quadrant Strategies

And our collaborators:

Winning Strategies Washington

Alpine Group

With special thanks to Kristina Dunklin, Nancy Fox, and Mike Merola

Thank You to our Leadership

Congressional ALS Caucus members

2023 Board of Directors:

Sandra Abrevaya

Peter Bowen

Jano Cabrera

Jenny Fortner

Louise Langheier

Michael O'Neil

Neel Parekh

Peggy Plews-Ogan

Juan A. Reyes

Michael Slaby

Dan Tate, Jr.

Brian Wallach

Former Board of Directors:

Edwin Cohen

Clare Durrett

Jessie Rossman

Divya Silbermann

2023 Committee Co-Chairs:

Clinical Trials

Bob Hebron

Diane Hoey

Daniel McIntyre

Community Outreach

Tim Abeska

Juliet Taylor

Familial ALS

Kimberly Hope

Debbie Lower

Legislative Affairs

Nicole Cimbura

Troy Fields

Glen Rouse

Jack Silva

Lou Gehrig Day

Maria Aleandra

Doug Butchart

Many Shades of ALS

Katrina Byrd

Juan Reyes

Thank You Squad

Abby Sims

Mo Tombrello

The Write Stuff

Katrina Byrd

Shelly Hoover

Juliet Taylor

Veterans Affairs

Mandi Bailey

Shelly Hoover

Young Adults

Ashley Lee

Lastly, but most importantly, we owe so much of our progress and success to those who are no longer with us. We dedicate this report to all the incredible people we've lost to ALS. Watch the video below to get to know some of those we lost in 2022.

The logo for the ALS Association, featuring the text "IAM ALS" in a blue, stylized font. "IAM" is in a smaller, sans-serif font, and "ALS" is in a larger, bold, sans-serif font. A horizontal line is positioned below the "AM" part of "IAM".

IAM ALS