The ALS Revolution

I AM ALS

Annual Report

2023

Table of Contents:

Welcome

As we reflect on the 2023 journey for I AM ALS, the first thing that comes to mind is Embracing Hope. We are hopeful because of our dedicated volunteers, and immensely grateful to the community for their work in line with this mindset. This report is more than numbers; it is a testimony to the power of collective action, shared determination, and an unwavering commitment to hope.

In the face of adversity, our shared vision for an ALS-free, and a neurodegenerative disease-free, world propels us. Founded on the belief that together we redefine possibilities in the fight against ALS, I AM ALS thrives due to our community's selfless contributions. This year was marked by milestones, challenges, and resilience. 2023 efforts resulted in increased funding, awareness, and advocacy for transformative policies. Stories of courage fuel our commitment to embrace hope in pursuit of effective treatments and a cure.

As you delve into this report, we encourage you to celebrate your victories, acknowledge challenges, and recognize the profound impact we've made together. Thank you for being an integral part of this journey.

With hope and gratitude,

Brian Wallach
Co-Founder, I AM ALS

&

Sandra Abrevaya
Co-Founder, I AM ALS

END ALS

END ALS

END ALS

Our History:

Brian Wallach was diagnosed with ALS at just 37 years old: a 100% terminal disease that slowly robs people of their ability to move, speak, and eventually breathe.

He and his wife Sandra Abrevaya, both political veterans, founded I AM ALS in 2019 to make sure that ALS voices are heard by building a patient-led movement.

I AM ALS is now a five-year-old patient-centric organization driven to end ALS and other diseases.

Our Mission:

Organize:
We mobilize and build communities to raise awareness of ALS, improve the ALS therapy pipeline, and improve the quality of life for people living with ALS and their loved ones.

Support:
We support people living with and impacted by ALS as they navigate the system, access resources, and build community.

Advocacy & Awareness:
We empower people living with and impacted by ALS to build awareness, increase federal funding, and influence policies for the ALS community.

MISSION

MISSION

2023 Federal Research & Treatment Impact

Expanding Care Access + Improving Quality of Life + Growing the Movement

$75 million annually for Expanded Access Programs (EAP) + 4 Expanded Access Programs

$40 million annually for the DOD Congressionally Directed Medical Research Program (CDMRP)

Tofersen approved by FDA, now known as Qalsody

2023 Support & Quality of Life Impact

Expanding Care Access + Improving Quality of Life + Growing the Movement

Supported
300 new clients
living with and
impacted by ALS

46,000 people
accessed
resources through
the Online
Resource Center

The Elizabeth Dole
Home Care Act
passed the House, a
step in improved
caregiving services

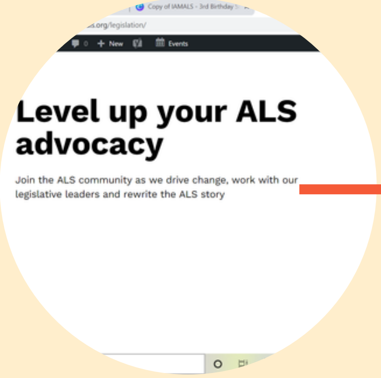
Hosted 95
support groups

2023 Movement Impact

Expanding Care Access + Improving Quality of Life + Growing the Movement

467 ALS advocates joined to push for increased ALS funding

Followers on social media grew by 9%



Level up your ALS advocacy

Join the ALS community as we drive change, work with our legislative leaders and rewrite the ALS story

28,000+ online advocacy actions taken

825 students and medical experts educated about ALS through the Tim Lowrey ALS Panel Series

119 events hosted with over 13,000 participants

236 community members served on I AM ALS community teams

ADVOCATE

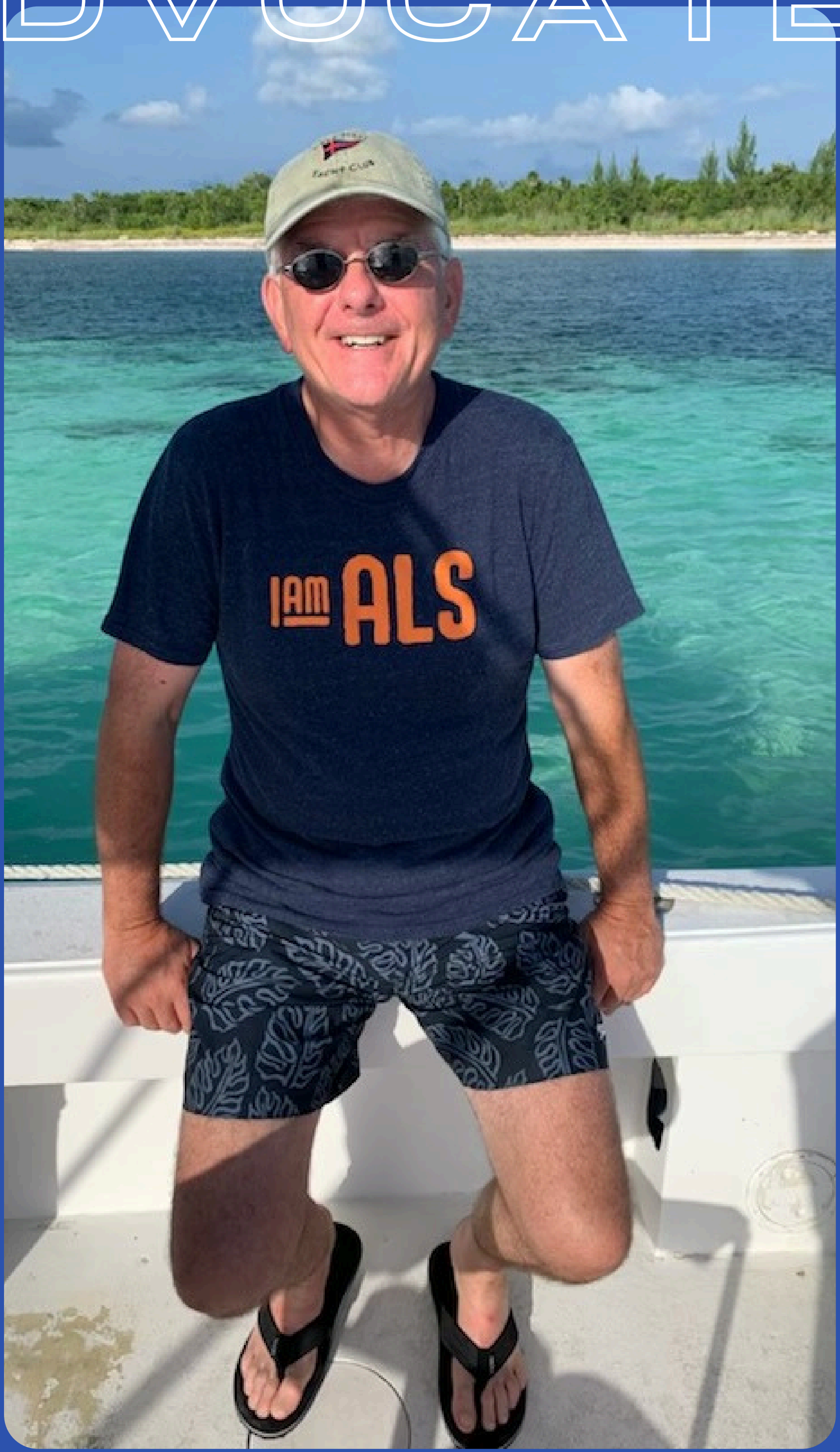
> As a person living with ALS, I AM ALS has brought me a true sense of community, specifically on the Veterans Team, where I have found new family members in what can be an extremely isolating lifestyle. I have found [I AM ALS] to be filled with compassionate and understanding people who relate to my daily challenges.

- Juan Reyes, volunteer & board member

ADVOCATE

> The Community Outreach Team promotes the Tim Lowrey Panel Series, and presents panels to educate medical professionals and students about ALS, to raise awareness, and stimulate interest in joining our advocacy efforts. 26 panels were presented during 2023. This undertaking is a source of pride for me and the entire team.

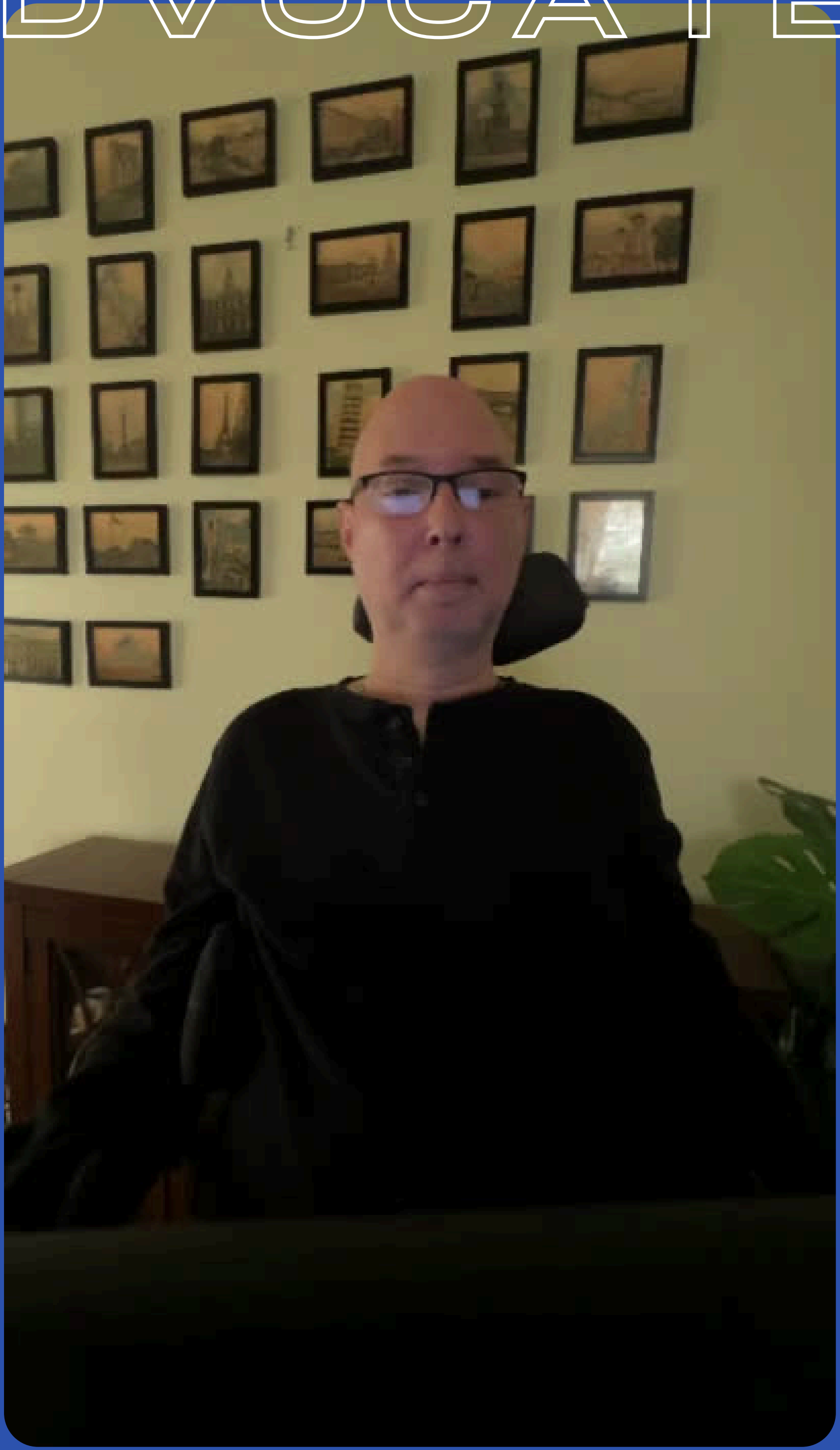
- Tim Abeska, volunteer



ADVOCATE

> As a man of Hispanic descent living with ALS, The Many Shades of ALS team provides a space for me and other minorities to openly share our experiences while finding and giving the support we need. As a person living with this disease, I AM ALS has brought me a renewed sense of purpose since my diagnosis.

-Troy Fields, volunteer



ADVOCATE

> ALS took my husband Jeff from me just 19 months after his diagnosis. I take pride in being a community team member at I AM ALS to let fellow community members know there will be peaks and valleys in their journeys, but they are never alone. I AM ALS has given me the ideal place to share my dedication to finding a cure for this ‘thief of a disease’ and help in my grieving process.

- Juliet Taylor, volunteer

COMMUNITY

I am in awe of how well matched my mentor and I are. Great job! Though her ALS journey started a whole year ahead of me, my fast progression kind of places us at a similar place which is great because we are able to compare notes and learn tips and tricks to help us try our best to remain independent for as long as we can. All and all, compliments to the ALS "matchmaker". My mentor is a 100% success story.

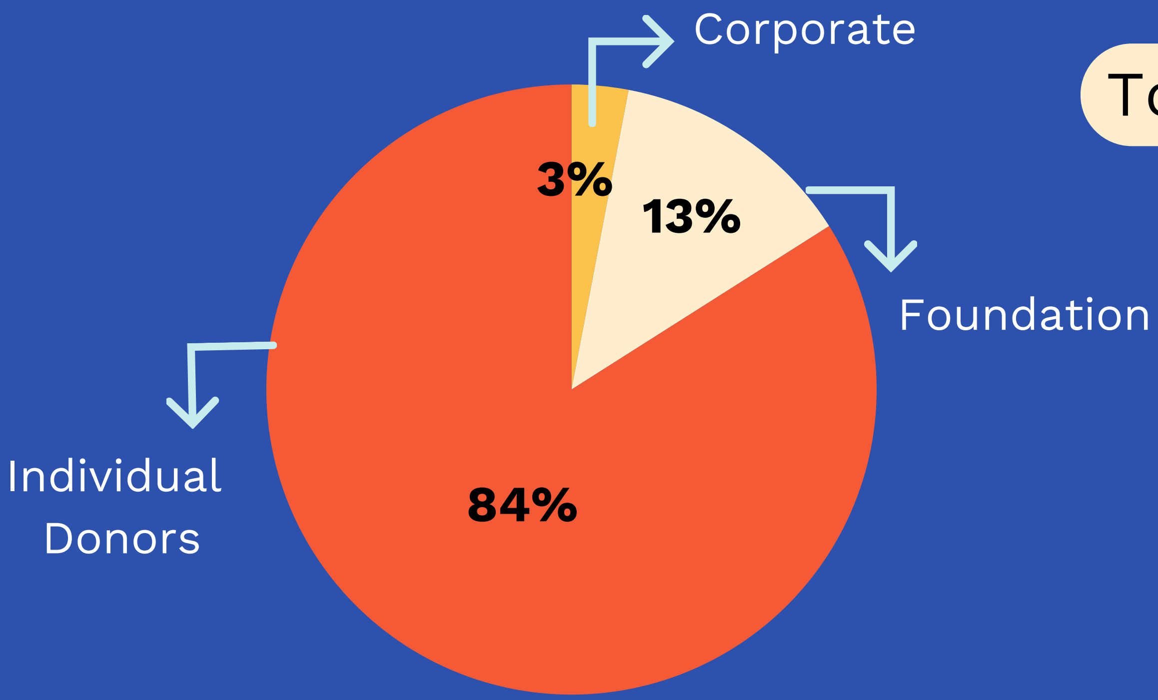
- Monique, Peer Support Initiative participant

My mentor rocks and I would definitely be lost without her help! She's a great resource and I'm so thankful to I AM ALS for developing such a great mentor program.

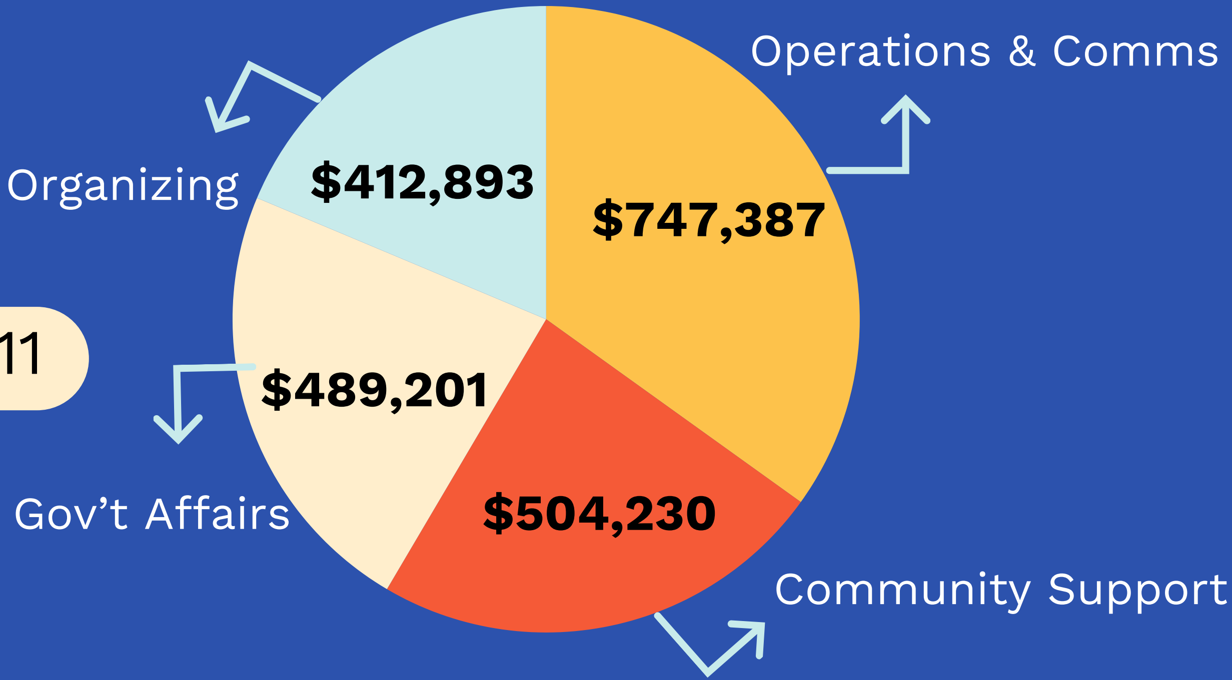
- Caregiver, on her experience with the I AM ALS Peer Support Initiative

Financials:

Total Revenue: $2,327,577



Total Expenses: $2,153,711



Thank You to Our Supporters

We would not have been able to accomplish all of the above successes without our incredible donors and fundraising champions at all levels. Every dollar makes this work achievable.

We want to give a special, heartfelt thanks to the following 2023 supporters of $100,000 or more:

Poarch Band of Creek Indians
Judy and Peter Blum Kovler Foundation
Rosenthal Family Foundation
Divya and Ben Silbermann

As well as the following 2023 supporters of $25,000 or more:

The Hummingbird Fund
NHL Seattle Foundation
Connie Ballmer
Joe and Carson Gleberman
Jeff McNatt
Scott Purviance
Rosenthal & Rosenthal
Ben and Shannon Sloop
Klei Family Charitable Fund

Thank You to Our Community Teams

Clinical Trials

Chairs:
Bob Hebron
Diane Hoey
Daniel McIntyre

Community Outreach

Chairs:
Tim Abeska
Juliet Taylor

Familial ALS

Chairs:
Kimberly Hope
Debbie Lower

Legislative Affairs

Chairs:
Glen Rouse & Garrett May
Jack Silva & Troy Fields
*Nicole Cimbura
*Becky Mourey

Lou Gehrig Day

Chairs:
Cristy Hardin
*Maria Aleandra
*Doug Butchart
*Lorri Carey

Many Shades of ALS

Chairs:
Kendra Womack
*Katrina Byrd
*Juan Reyes

Thank You Squad

Chairs:
Katie Kirkpatrick
Gia Polo
*Abby Corsun Sims
*Maureen Tombrello

The Write Stuff

Chairs:
Juliet Taylor & Elin Adcock
Emily Cerbone & Cristy Hardin
*Katrina Byrd
*Shelly Hoover

Veterans Team

Chairs:
Lara Garey
*Mandi Bailey
*Shelly Hoover
*Mary Hahn Ward

Youth Lou Gehrig Day

Chairs:
Brian Andre
Ginger Hancock
Sue Hiller

*Past Co-Chair

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

PICTURED:

Back Row: Jano Cabrera; Peter Bowen; Michael O'Neil; Michael Slaby; Neel Parekh; Andrea Goodman; Jenny Fortner; Stephanie Kapsis; Winona Koldyke

Front Row: Meg Reyes; Juan A. Reyes; Sandra Abrevaya; Brian Wallach; Jim Plews-Ogan; Peggy Plews-Ogan; Louise Langheier

Letter from the CEO:

I am filled with both gratitude for what we achieved together in 2023 and also eagerness to continue on our urgent journey ahead. Looking back at the challenges we faced and the triumphs we celebrated in the past year, it is clear that this organization's superpower lies not just in our mission to defeat ALS, but in the collective hope that binds us together. Even in times of uncertainty and pain, a sense of togetherness has fueled our progress, enabling us to break new ground and amplify our impact.

In addition to maintaining the foundation of our community support and volunteer teams, I am excited to share new 2024 activities:

- Develop strategies to expedite access and approval processes for ALS treatments.
- Establish a Cures Coalition to unite the ALS and neurodegenerative community for advocacy and awareness.
- Host the inaugural ALS Community Summit, enhancing connections and awareness.
- Expand support services with a peer support specialist program.
- Advocate for federal improvements benefiting families affected by ALS.

Hope will continue to be our guiding principle. Together, we can turn hope into action, reshaping the future for people affected by ALS.

With hope and thanks for your support,

AGoodman

Andrea Goodman
Chief Executive Officer

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#endALS

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I AM ALS

www.iamals.org