



2024

Participant Guide

*A User Guide for Your Best
Walk Day Experience*





2024 Walk to Defeat ALS

WALK YOUR WAY

to help make a difference!

WALK ON YOUR OWN

JOIN A WALK EVENT!



OR



WALK + TALK

Who we are. What we do.

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.

Our Goal: To make ALS a livable disease for everyone, everywhere until we can cure it.

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. Eventually, people with ALS lose the ability to initiate and control muscle movement, which often leads to total paralysis and death within two to five years of diagnosis. For unknown reasons, veterans are twice as likely to develop ALS as the general population. There is currently no known cause or cure.

The ALS Association is the only national nonprofit organization fighting ALS on every front. By integrating local care services, cutting-edge global research, and nationwide advocacy on behalf of those living with ALS, the Association builds hope and enhances quality of life while urgently searching for new treatments and a cure.

OUR VISION: **Create A World Without ALS**

Your Donations Help Fund Research:

The ALS Association is the largest philanthropic funder of ALS research in the world.

Thanks to your support, we have been able to commit **over \$42.5M to fund ALS research around the world.** We currently support 165 active research projects in 13 countries (including U.S.).

We are bringing effective treatments to our ALS community, including **Qalsody (tofersen)** for people living with ALS with mutations of the SOD1 gene and **Relyvrio**, the first FDA-approved drug for the treatment of ALS funded by ALS Ice Bucket Challenge donations.

This year we launched a new grant program to fund research infrastructure into **expanding clinical trial capacity** and provided support that led to the development of a cutting-edge platform trial



Unlock ALS

THE KEY TO THE CURE STARTS WITH YOU

These keys represent our commitment to unlocking

- the physical constraints which threaten a person with ALS everyday
- the barriers to effective and compassionate care
- the medical mysteries which will someday lead us to a cure

What Color is Your **KEY**?


GOLD:
I have ALS


WHITE:
I have lost someone to ALS


BLUE:
I'm walking in honor of someone with ALS


RED:
I support the cause and want to defeat ALS

Your Donations Help Fund Care:

Last year, we served **21,654** people with ALS, including **2,081** military veterans. We also hosted support groups attended by **29,957** people.

We have expanded our clinical partner network to include **79 Certified Treatment Centers of Excellence** and **18 Recognized Treatment Centers** to provide ALS multidisciplinary care across the U.S.

Last year we provided **\$4.8 million in grants** to support our certified center program.

To date, we have provided **over \$1.5 million in scholarships** to students who have been impacted by ALS.

How **YOU** Can Help:

AT A WALK EVENT OR AT HOME!

**YOU'VE ALREADY TAKEN THE MOST IMPORTANT STEP:
REGISTERING FOR THE WALK TO DEFEAT ALS.**

What's Next?



Make A Donation:

Lead by example and show your commitment to the cause by making the first gift to your campaign.



Share Your Why:

Update your personal page and share your connection to ALS.



Get Social:

Set up a Walk to Defeat ALS Facebook Fundraiser through the participant center to reach a broader social network.



Customize Your URL:

Create your own URL to share with family, friends, and co-workers. Post it on social media or add it to your email signature so people can easily find your page.



Recruit Friends:

Grow the movement to cure ALS by asking your network to join you.



Send Emails:

Prewritten templates make it easy to ask your contacts for support right from your participant center.



Go Mobile:

Download the **Good Move** mobile app to fundraise from the palm of your hand — anytime, anywhere!

Your Donations Help Fund Advocacy:

We have mobilized more than 40,000 advocates in recent years to increase federal funding for ALS research.

Funding has increased at the National Institutes of Health from \$48 million in 2014 to \$124 million in 2022 and at the Department of Defense from \$5 million in 2008 to \$40 million in 2022. Also \$5 million in NEW funding specifically for ALS research began at the FDA in 2022.

We mobilized more than 5,000 advocates to send a message to Congress to support permanent access to telehealth.

Become an ALS Advocate!

You can help change laws and policies that impact people living with ALS and their loved ones. Visit als.quorum.us/register to become an ALS advocate today.

FAQ:

YOUR ONE-STOP SHOP FOR ALL THOSE NEED-TO-KNOWS

? I forgot my username and/or password. Help?

a No worries! Contact your Walk coordinator. They can help!

? Do you store email addresses?

a The contacts you upload are available for your eyes only! Your contacts stay attached to your record but the ALS Association cannot see the information.

? My friend won't be at the Walk but still wants to help. How can they?

a Those who won't be present at the event can register as virtual participants on your team. They will still receive the same online fundraising tools to make it easy to support, even from far away.

? I'm not the team captain but I still have a fundraising page. Did I register wrong?

a Nope! Everyone on the team has a page and access to the same fundraising tools the team captain does. All funds you and the other team members raise will roll up to the team total.

? I made a donation but it's not showing up on my page. Did it go through?

a More than likely it just got credited incorrectly. Check with your Walk staff and they can help track it down for you and apply it to your page.

? My supporters prefer to make a donation by check or cash rather than online.

a No problem! You can also print an offline donation form right from the bottom of your personal page! Use that to mail in checks to ensure they are credited correctly.

? What happens if no one donates?

a Don't give up! The average person receives 100 emails a day. If you haven't heard back from a friend, chances are they overlooked your email. Don't be afraid to send another.



Let's **GET STARTED!**

EASY WAYS TO JUMPSTART YOUR FUNDRAISING



- 1** Kick things off with your own donation.
- 2** Challenge 2 family members to match your donation.
- 3** Connect your fundraiser to Facebook and invite 10 friends.
- 4** Share your fundraising page with 5 co-workers, on your next Zoom meeting.
- 5** Tell 4 of your neighbors how they can help reach your goal.
- 6** Encourage 5 friends to join you in supporting the cause.
- 7** Ask your boss for a company contribution. Better yet, find out if your company will match what you raise!
- 8** Track your progress and share your success!
- 9** Visit the FAQ section of the Walk Website for more Fundraising Tools!



DOUBLE YOUR DOLLARS | MATCHING GIFTS:

After all your fundraising work is complete, you still may be able to increase your impact on the fight against ALS. Many companies will match their employees' charitable contributions. Be sure to check with your employer and ask your supporters to as well! You can also visit www.matchinggifts.com/als to see if your company participates. Don't forget to talk to your company about forming a corporate team too!

Reach out to your Walk coordinator and ask for posters, brochures, or other items to help promote the Walk. Ask local restaurants or community gathering places to display them to help spread the word!

GET STARTED "WRITE" AWAY | SAMPLE LETTERS AND EMAILS:

Check out the sample letters available on the website or create your own and send it out to friends and family asking for support. Include the story of WHY the Walk is important for you and share a photo if you have one!

SIZE IT UP | TEAM T-SHIRTS:

NEW FEATURE! The ALS Association has partnered with Bonfire to provide teams with a risk-free, cost-free, and fun way to fundraise for Walk to Defeat ALS. Get creative and design custom t-shirts for your team today through your Participant Center.

GET INVOLVED | KICK OFF, TEAM WEEK, AND CONTESTS:

Attend the kickoff party to meet other Walk participants and pick up supplies to ensure your fundraising success. Encourage your team to participate in Team Week and other contests throughout the year for your chance to win cool Walk swag!

BE CREATIVE | PUT THE FUN IN FUNDRAISING:

Use your interests and hobbies as a way to boost your fundraising! Love fantasy football? Use half your league buy-in as a Walk donation. Do you paint, knit, or record music? Sell your art for donations!

COMMUNICATE OFTEN WITH YOUR TEAM TO MOTIVATE AND ENCOURAGE THEM:

Make a donation to your cause and provide fundraising suggestions to get to your goal!



Ideas to **WALK YOUR WAY!**

There are many innovative ways for virtual participants and teams to Walk Your Way. Here are some ways you can #WalkToDefeatALS wherever you are.



SHOW YOUR TEAM SPIRIT AND POST A PICTURE of you in your team t-shirt or holding a team sign. Use #WalkToDefeatALS and tell us why you walk.



SHARE HOW YOU'VE CHALKED YOUR WALK – draw start and finish lines or share messages of gratitude throughout your neighborhood.



HANG YOUR WALK DAY POSTER – color your key, hang it in your window and tell us why you Walk To Defeat ALS.



MAP YOUR ROUTE AND DISTANCE – in our Walk to Defeat ALS app and explore our activity challenges.



HOST A WALK YOUR WAY – walk with your family and friends on a date and at a location of your choice.



ALS Ice Bucket Challenge

THE ALS ICE BUCKET CHALLENGE WAS A GLOBAL PHENOMENON THAT CHANGED THE FIGHT AGAINST ALS FOREVER.

IN THE SUMMER OF 2014, THREE YOUNG MEN STARTED THE ALS ICE BUCKET CHALLENGE. They inspired people around the world to dump ice water on their heads and donate to an ALS organization. Over 17 million people participated in the Challenge and raised \$115 million for the ALS Association.

“The Ice Bucket Challenge dramatically accelerated the fight against ALS. Since then, we’ve seen new genes discovered, new assistive technology developed to help people living with ALS, and far more people living with ALS have access to care services than ever before.”

– Calaneet Balas, ALS Association President and CEO

This year, we're celebrating the 10 year anniversary of the ALS Ice Bucket Challenge. Learn more at als.org/ibc



THANK YOU To Our Sponsors!

As a Walk to Defeat ALS Partner these organizations have an immediate impact on unlocking the mysteries of ALS.

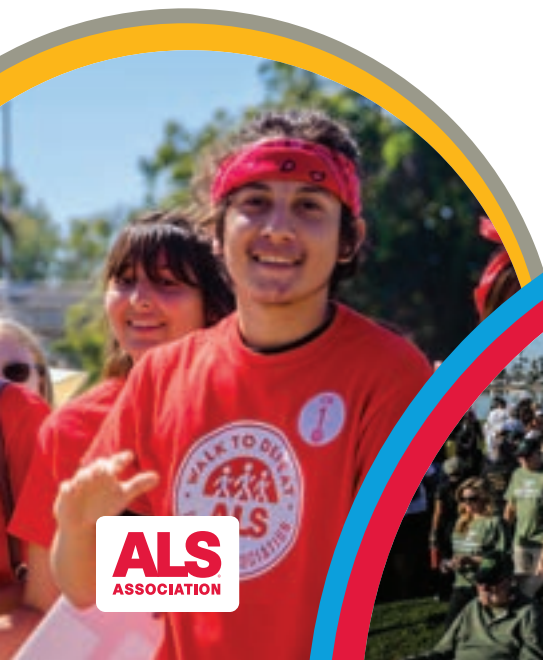
NATIONAL PARTNERS



Change the future of ALS:

Become a Legacy Society member today.

als.plannedgiving.org



ALS
ASSOCIATION
als.org