AUGUST KICKOFF



Tuesday, August 1 at 3pm ET



2023 ALS ASSOCIATION SPONSORS













2023 ALS ASSOCIATION SPONSORS













WELCOME

CALANEET BALAS **CEO ALS Association**



ADVOCACY ALS ACTION MONTH

Why Advocacy is Important







Why Advocacy is Important







ALS Research: Why More Research Is Critical

KULDIP DAVE, Ph.D.
Senior Vice President, Research



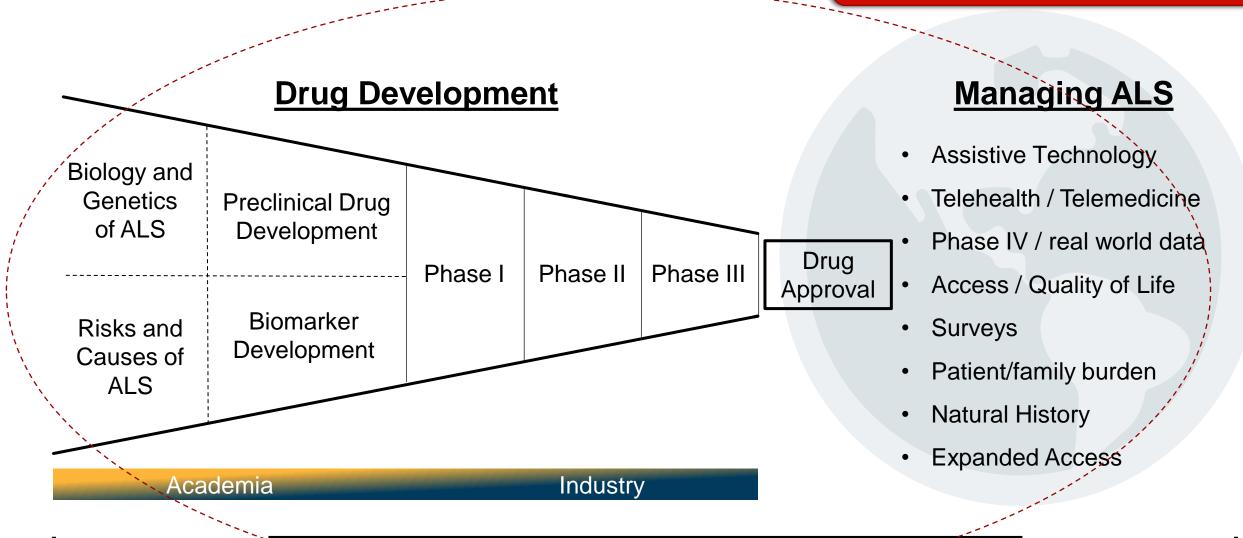
The ALS Association is the Largest Philanthropic Funder of ALS Research

The Funding Process

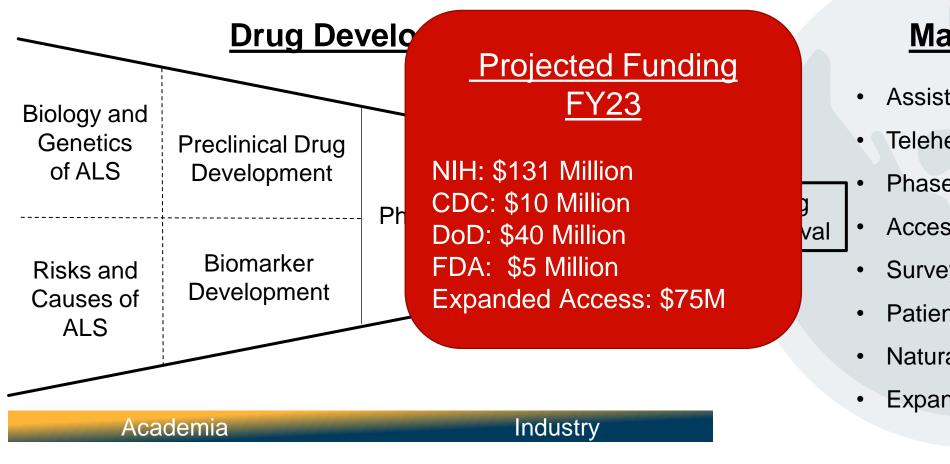
- · Identify areas of need
 - Work with our community to identify gaps and opportunities
- Request and review applications
 - Targeted requests for applications
 - Rigorous three-step review process
- Fund the best projects
 - Around the world
 - Academia, industry, government or other non-profit organizations

Our 2022 Research Funding

- Issued 7 Requests for Applications
 - Topics across the ALS research ecosystem
- Reviewed 245 applications
 - From 18 countries, 29 states,
 Washington DC and Puerto Rico
- Committed \$15 million to fund 59 new projects



Current Congressional Funding of ALS Research



Managing ALS

- Assistive Technology
- Telehealth / Telemedicine
- Phase IV / real world data
- Access / Quality of Life
- Surveys
- Patient/family burden
- Natural History
- **Expanded Access**

Current Congressional Funding of ALS Research – NIH



- Research: \$131M
 - Expanded Access: \$75M

Drug Development

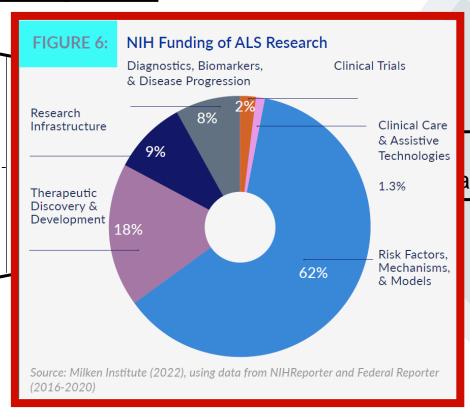
Biology and Genetics Preclinical Drug

Risks and Causes of ALS

of ALS

Biomarker Development

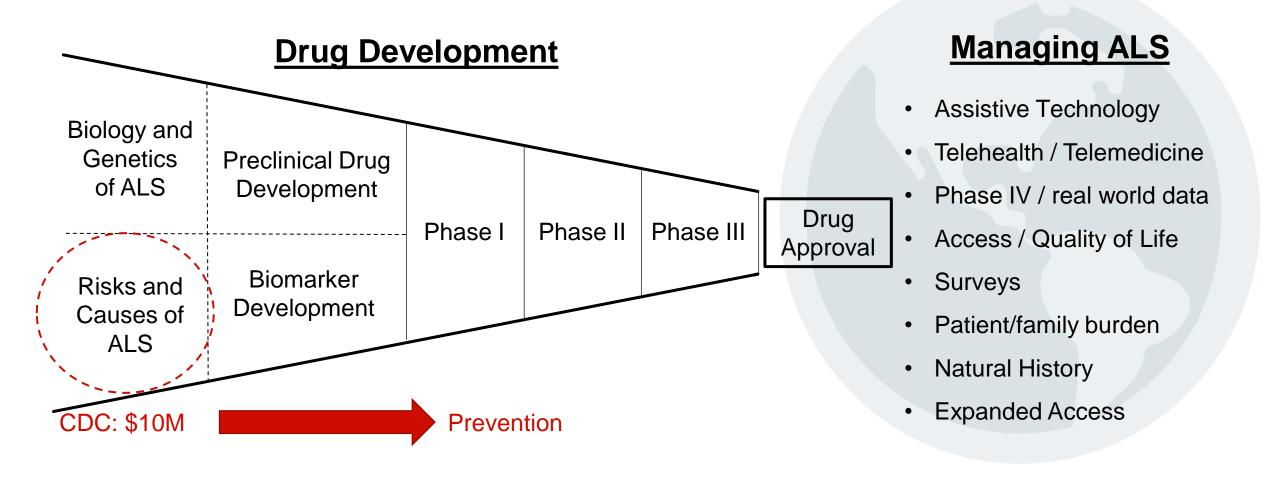
Development



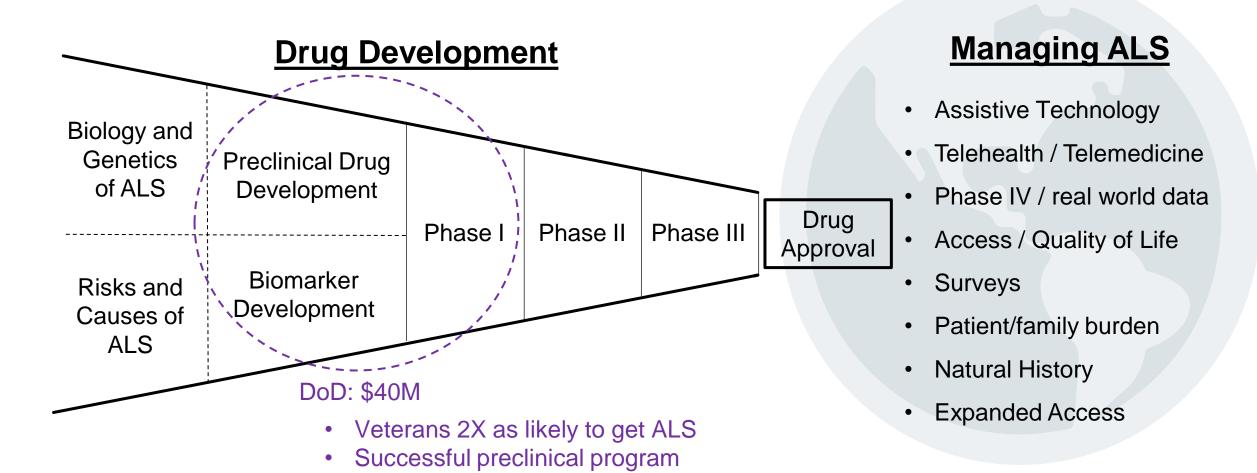
Managing ALS

- Assistive Technology
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- Natural History
- Expanded Access

Current Congressional Funding of ALS Research – CDC

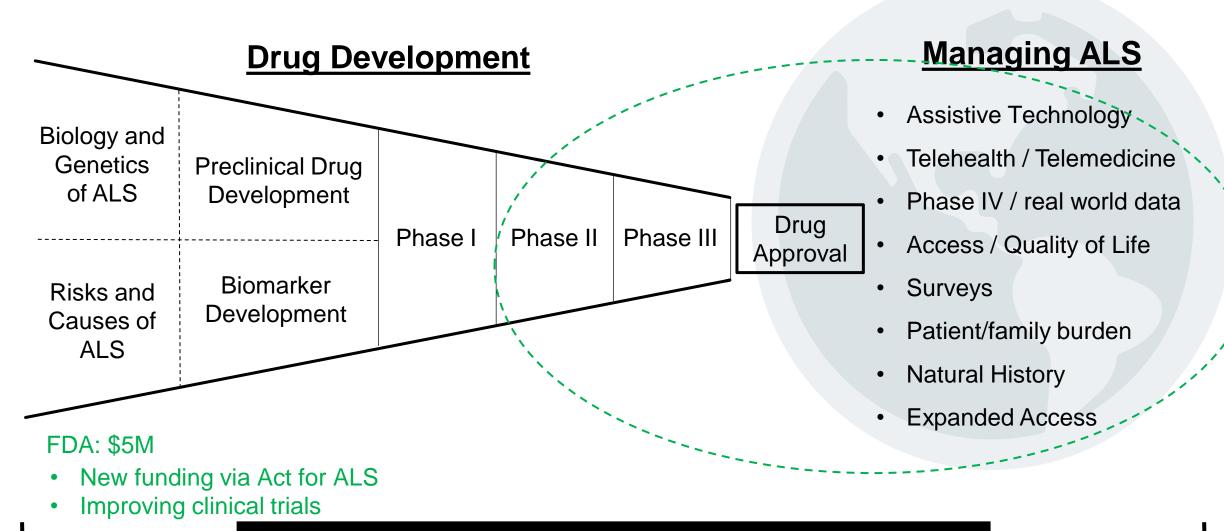


Current Congressional Funding of ALS Research - DoD



Clinical research is more expensive

Current Congressional Funding of ALS Research – FDA



Current Congressional Funding of ALS Research

NIH: \$131M Research

NIH: \$75M Expanded Access

Drug Development

Managing ALS

Biology and Genetics of ALS

Risks and

Causes of

ALS

Preclinical Dru Developmen

Biomarker Developmen

DOD: \$40M

Conclusions

- Each agency is unique
- The ALS Association fills in the gaps and leads the way to new opportunities
- All must work together to advance the ecosystem as a whole

Assistive Technology

- Telehealth / Telemedicine
- Phase IV / real world data
- Access / Quality of Life
- Surveys
- Patient/family burden
- Natural History
- Expanded Access

CDC: \$10M

FDA: \$5M



ALS RESEARCH APPROPRIATIONS

DENISE BAILIN

Director, Congressional Affairs





















WHAT WE ARE ASKING CONGRESS

OUR ASKS FOR ALS APPROPRIATIONS



Summary: ALS Research Appropriations Asks

We Cannot Slow Down ALS Research!

- ALSRP: \$80 million for the Department of Defense ALS Research Program (ALSRP)
- NIH: \$150 million for research at the National Institutes of Health
- ACT for ALS: Provide full funding for the ACT for ALS Act - \$100 million
 - \$25 million FDA
 - \$75 million NIH
- CDC: \$15 million for the National ALS Registry and Biorepository





ALS robs people of the ability to

ADVOCACY ACTION MONTH OVERVIEW

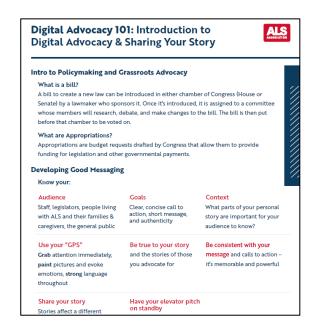
DUSTIN PERCHAL

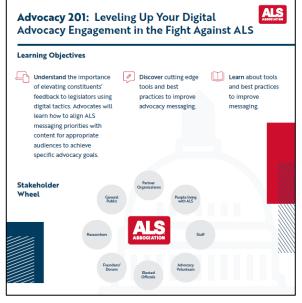
Director, Advocacy Engagement & Mobilization The ALS Association

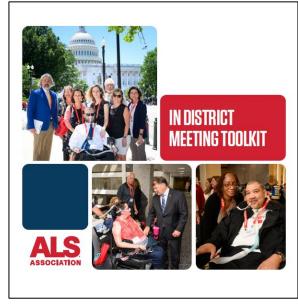


JULY ADVOCACY TRAININGS

- In-District Meeting Training (Recording available from ALS staff partner)
 - Volunteers & Staff attending 42 key appropriations lawmaker meetings
- Advocacy 101 Training (Recording available on website)
 - Introduction to Digital Advocacy & Sharing Your Story
- Advocacy 201 Training (Recording available on website)
 - Leveling Up Your Digital Advocacy Engagement in the Fight Against ALS









8 WAYS TO TAKE ACTION: ALS.org/August



















Drop-By Info



Send Letter





Share Story



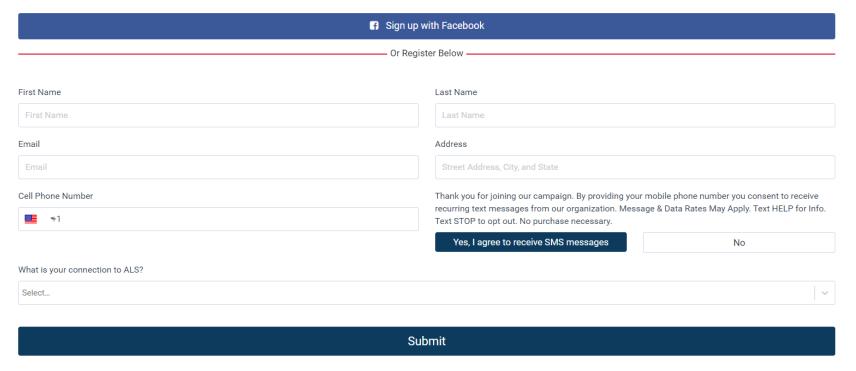


www.als.org/August



BECOME AN ALS ADVOCATE

Sign Up







www.als.org/August



SIGN UP FOR **ADVOCACY** TEXT ALERTS!

Text "ALS" to 855-469-2621



ALS ADVOCACY ACTION **MONTH**



AUGUST ADVOCACY ACTION SCHEDULE

- Aug 1: Action Month Action Alert #1 Write Letter to the Editor
- **Aug 8: Action Month Action Alert #2 Call District Offices & Tweet**
- Aug 15: Action Month Action Alert #3 Office Drop-By & Tweet
- Aug 22: Action Month Action Alert #4 Write a Letter & Tweet
- Aug 29: Action Month Action Alert #5 **Share Your Story**







Send a Letter

research letter and send it to

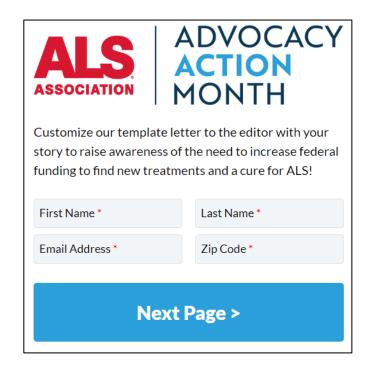
your Member of Congress.

Use Social Media Tweet your Member of Congress and ask them to increase ALS research



Learn more at als.org/advocacy

WRITE A LETTER TO THE EDITOR











WRITE A LETTER TO THE EDITOR

300 WORD LIMIT

Urgent: Increase Not Cut Federal ALS Research Funding

Dear Editor,

I am writing to express my deep concern regarding a devastating lack of funding for amyotrophic lateral sclerosis (ALS) research in the federal budget. ALS, also known as Lou Gehrig's disease, is a rare and devastating neurodegenerative disease that affects thousands of Americans. ALS can impact anyone, but it impacts those who serve in the military at a higher rate. In fact, the Veterans' Administration has declared ALS a service-connected disease.

ALS causes motor neurons to degenerate over time until they eventually die. There is no cure for ALS and as the disease progresses, people lose the ability to speak, eat, move, and breathe. Life expectancy can be less than five years after diagnosis. Funding for ALS research is essential to drive scientific advancements, develop innovative therapies, and improve the quality of life for ALS patients.

Research investments in other serious diseases, such as cancer and Alzheimer's, have resulted in breakthroughs in new treatments. No treatments were available for ALS for many years, but previous federal investments have led to two new FDA-approved drugs that can delay symptoms.

However, funding for ALS dramatically lags behind other diseases and must be increased. Without new and larger investments from the federal government, people living with ALS will be denied opportunities for new treatments and cures.

As a concerned citizen, I call on my Senators and Representative to increase, not cut federal ALS research funding in the 2024 budget at NIH, the Department of Defense and other relevant agencies. With greater investments, scientists and researchers can find treatments and cures for this devastating disease – and discover how to prevent it.

Together, we can make a difference and bring us closer to a future where ALS can be a livable disease.







CALL YOUR DISTRICT OFFICES

Call Your Rep.'s District Office & Ask Them to Support ALS Research Funding

Call your Member of Congress at their district office while they are back home for August Recess and ask them to support our ALS research funding requests for the 2024 federal budget.

We have a draft script that you can customize and use when making your call. Most calls are very short lasting one minute or less as DC offices are very busy. You might also be prompted to leave a voicemail.

To begin, click the blue box under the script and you will be receiving a call immediately that will connect you to your Member of Congress.

Then a text box will appear so you can let us know how the call went. When finished, click submit.

Please note: You must have provided your phone number for the system to call you. To update your phone number, click on your name in the upper right-hand corner at the very top of the page, then select "Update Information" from the drop-down menu.

We are also sensitive to the fact that some people living with ALS will not be able to make calls into district offices. We are thankful for other ALS advocates including ALS caregivers who can provide a voice for those who are not able to physically use theirs. Together we can advocate for the entire ALS community.

Call Your Representative - Click Below to Call

Script

Hi - I'm Dustin Perchal from Arlington, VA.

I am a constituent and someone who has been impacted by ALS.

There is no cure for ALS and there are few treatments available.

It is critical that we increase ALS research funding to find new treatments and cures.

I am calling to ask for Representative Beyer to increase ALS research funding. Specifically:

- \$80 million for the Department of Defense ALS Research Program,
- \$150 million for the National Institutes of Health,
- \$100 million for the ACT for ALS, and
- \$15 million for the National ALS Registry and Biorepository

We need your help to find a cure and prevent ALS.

Can I count on Representative Beyer to support ALS research funding at these levels?

--- {WAIT FOR RESPONSE FROM OFFICE STAFFER ON PHONE} ---

Thank you for your time!

Click here to call the Arlington District Office of US Representative Don Beyer at (703) 658-5403







DISTRICT OFFICE DROP-BY

Drop-by the District Office of Your Members of Congress

OFFICE DROP-BY INSTRUCTIONS:

During the August Recess, many constituents drop-by district offices of their Members of Congress.

You can download and print our ALS Research Funding One Pager to deliver to your federal lawmaker's district offices during the August Recess.

Your message for your Members of Congress and their staff during the delivery is the following:

- "I'm a constituent of Rep./Sen. [X] and I've also been impacted by ALS, a fatal disease without
- I'm here to ask Rep./Sen. [X] to support increases, not cuts, in federal funding for ALS research in the 2024 budget.
- · Research is the only way we can stop ALS from destroying more families.
- · Here is a one pager with detailed information for you.
- Will Rep./Sen. [X] stand with the ALS community and support research funding increases in the 2024 budget?"

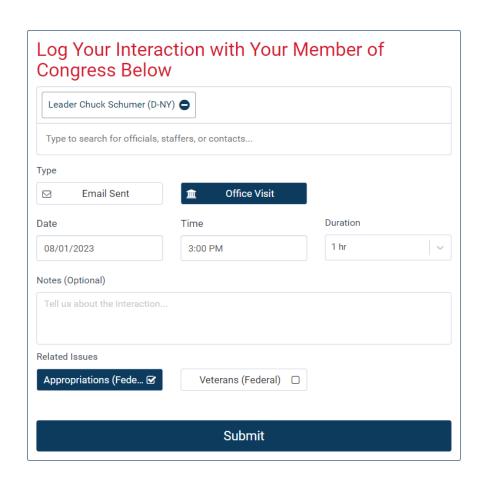
Once you have completed your delivery, log your interaction using the report back tool on this page to share with us how it went and who you spoke with.

Alternatively, if you have existing relationships with district office staff, you can also email the ALS Research Funding One Pager to your office contact. Once you have sent your email, please also let us know about your outreach by logging your interaction.

Here are links to assist you:

- · Find Your Lawmakers
- Search for Your Lawmaker District Office Information
- · Download ALS Research Funding One Pager PDF (To Print or Email)

If you have any questions, please reach out to the ALS Association Advocacy Team via email at advocacy@als.org.









DISTRICT OFFICE DROP-BY

ALS Research Funding



FY2024

Provide HOPE to thousands impacted by ALS by supporting the FY2024 Federal ALS Research Funding Asks:



\$80M

for the Department of Defense ALS Research Program



\$150M

for the National Institutes of Health



\$100M

for ACT for ALS



\$15M

for the National ALS Registry and Biorepository



What is ALS?

ALS, or amyotrophic lateral sclerosis, is a progressive disease in which a person's brain loses connection with the muscles, slowly taking away their ability to walk, talk, eat, and eventually breathe.

There is still no cure for ALS or treatment that halts progression. New treatments are helping to slow and ease symptoms.

- Every 90 minutes someone is diagnosed with ALS and someone passes away from it
- Average life expectancy is just 2-5 years
- Veterans are more likely to get ALS
- ALS can affect anyone, anywhere, at any time.

90% of cases have no known family history or genetic cause.

10% of cases are genetic, also known as familial ALS.

About the ALS Association

Established in 1985, The ALS Association is the only national nonprofit organization fighting ALS on every front. By leading the way in global research, providing assistance for people with ALS, and fostering government partnerships, The Association builds hope and enhances the quality of life while aggressively searching for new treatments and a cure.

We are the largest philanthropic funder of ALS research in the world, supporting projects from around the globe with the highest potential impact for people living with ALS and their caregivers. Since the Ice Bucket Challenge in 2014, we have committed over \$137 million to support more than 500 projects in the U.S. and 13 other countries, with the goal of making ALS a livable disease for everyone, everywhere until we can cure it.

Questions? Email: advocacy@als.org







SEND A LETTER



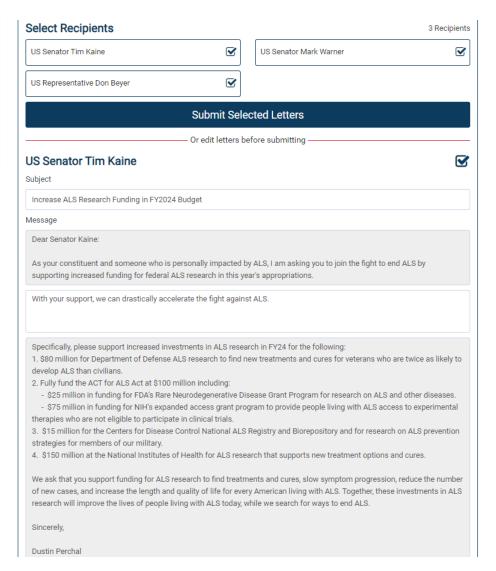
Tell Congress: Increase ALS Research Funding in 2024 Budget

Congress makes critical decisions about the future of ALS research through the annual appropriations process. Our top advocacy priority each year aims to increase federal funding to support research and the search for treatments and cures for ALS. Federal funding for ALS research and programs at the National Institutes of Health (NIH), the Food and Drug Administration (FDA), the DOD ALS Research Program and the CDC National ALS Registry must be increased exponentially to provide new treatment options to cure and prevent ALS.

Earlier this year, ALS champions Representatives Mike Gallagher (R-WI), Jason Crow (D-CO), Brian Fitzpatrick (R-PA), and Joe Courtney (D-CT) in the House of Representatives along with ALS champions Senator Chris Coons (D-DE) and Senator Bill Cassidy (R-LA) in the Senate released their letters asking colleague in each chamber to support increased federal funding for ALS research. Their colleagues responded with 80 U.S. Representatives and 32 U.S. Senators signing on to show their support!

However, the process is not over and each chamber is moving forward on deciding appropriations for 2024. They need to hear from you again about the importance of funding ALS research.

Urge your members of Congress to support increased federal funding for ALS research!









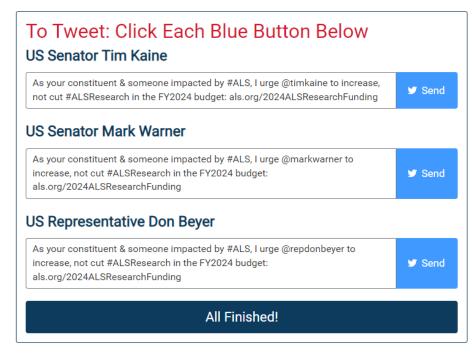
USE SOCIAL MEDIA



Tweet Your Members of Congress to Increase ALS Research Funding

If you have a Twitter account, **please click the blue button next to each tweet** to urge your U.S. Senators and U.S. Representative to support increased funding for ALS research.

Once all 3 have been tweeted, click the "All Finished!" button.



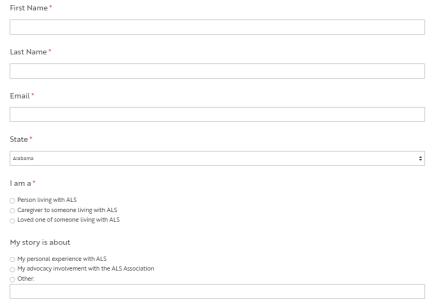






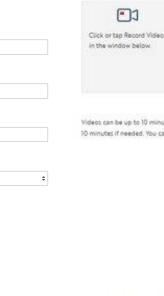
SHARE YOUR ALS STORY

Share Your Story with Us



Step-by-Step Instructions

1





Follow your phone or browser prompts to grant permission to use your device's microphone and comera.



Click the red Record button and start sharing your story.



Click the red record button again to stop recording when you are finished

Videos can be up to 10 minutes long. That we recommend keeping your story two under 2 minutes, you are welcome to use up to the full. 10 minutes if needed. You can also record as many takes as you need - just click the red button again to start another video.



If you would prefer to not share a video or would like to record a video separately, you may submit a pre-recorded video or audio recording through the file submission below.

were file No File Chosen

We also welcome you to share a photo of yourself and/or your loved ones with ALS to accompany any audio or text story submission.

Serveye File No File Choose.

Submit a written story

Any Pay TOO complementaries if you are not believed to salar triggs treat, you are managed the gap triangle that each assume

Consent*

() By submitting my story, I concent to the ALS Accordation sharing this content on their website social media and as testimonials during meetings with various statisholders









SHARE YOUR ALS STORY

Sort By State: Sort By Type:
Any Any

1 2 3 ... 8 Next »

Shane Mortimer

My mother Sandra was diagnosed in November of 2004. Her original symptoms started with restless legs. She had to constantly move them and had a terrible time trying to sleep. She wouldn't be able to push weights at the gym with her legs. After that, she was imping and used a cane. When she was diagnosed, the specialist said to take your shoes and socks off. Try to fit your foot and toes. She couldn't. He stopped and said 't believe you have ALS'. My heart dropped. We knew about ALS as we had a neighbor down the street who had it at a young age and passed. I was devastated. I could not believe it. My morn was upset but tried to look as unbeat as possible.

It was 9 months from her diagnosis to her passing. She went from healthy to a feeding tube and motionless. The stress my sister, father, and I had was nunwhelming. I still have the email of me nethod mad at the doctor who

Click to Expand

Nancy Weber

I will never forget the day my son called me to say that he had been diagnosed with ALS. He had been having trouble with his foot which bothered him quite a bit since he loved to hike in the Rocky Mountains. It took weeks and weeks to get this diagnosis. By that time he needed braces on his legs. From then on it was a honid three years because I was in Connecticut and he in Colorado, and we had to depend on my visits as often as possible and phone calls to stay connected. We were blessed because he did not lose his ability to speak, but whenever I saw him he was worse. He was given a medication to delay the symptoms but they didn't work as well as we hoped. He died at the age of 48 leaving a wife and 3 children.

I hope this story helps display how important early detection is. We need to increase awareness of ALS summaris in the medical profession. This is also

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Lois Dubin



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Angela Frederick



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Dawnn Tucker



Valerie Barrs-O'Mara









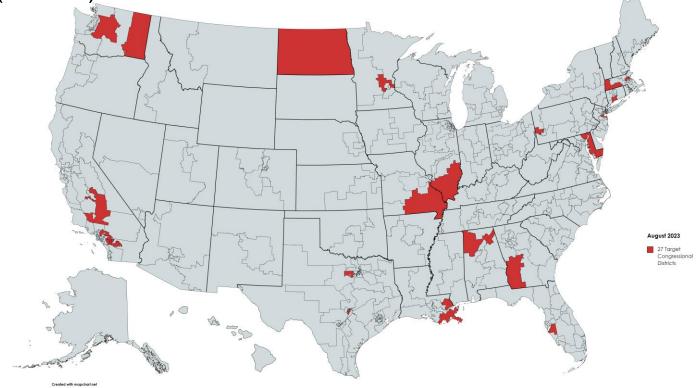
AUGUST KEY MEMBERS OF CONGRESS

House – 27 total

- •Leader Jeffries (D-NY-8)
- •Leader Scalise (R-LA-1)
- •Rep. Aderholt (R-AL-4)
- •Rep. Aguilar (D-CA-33)
- •Rep. Armstrong (R-ND-1)
- •Rep. Bishop (D-GA-2)
- •Rep. Bost (R-IL-12)
- •Rep. Buchanan (R-FL-16)
- •Rep. Calvert (R-CA-41)
- •Rep. Chu (D-CA-28)
- •Rep. Cole (R-OK-4)
- •Rep. DeLauro (D-CT-3)
- •Rep. Deluzio (D-PA-17)
- •Rep. Doggett (D-TX-37)

- •Rep. Granger (R-TX-12)
- •Rep. Harris (R-MD-1)
- •Rep. McCollum (D-MN-4)
- •Rep. McMorris Rodgers (R-WA-5) .
- •Rep. Meng (D-NY-6)
- •Rep. Neal (D-MA-1)
- •Rep. Pallone (D-NJ-6)

- Rep. Schrier (D-WA-8)
- Rep. Smith (R-MO-8)
- Rep. Takano (D-CA-39)
- Speaker McCarthy (R-CA-20)
- Whip Clark (D-MA-5)
- Whip Emmer (R-MN-6)

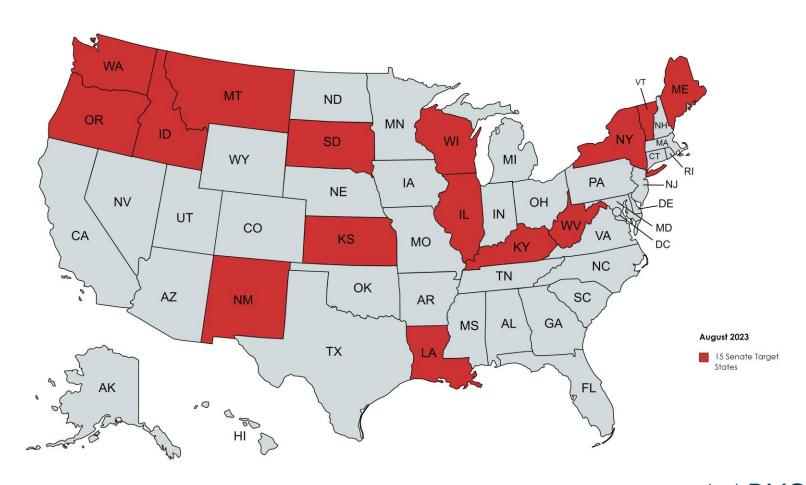




AUGUST KEY MEMBERS OF CONGRESS

Senate – 15 Total

- Leader McConnell (R-KY)
- Leader Schumer (D-NY)
- •Sen. Baldwin (D-WI)
- Sen. Capito (R-WV)
- Sen. Cassidy (R-LA)
- •Sen. Collins (R-ME)
- •Sen. Crapo (R-ID)
- •Sen. Heinrich (D-NM)
- •Sen. Moran (R-KS)
- Sen. Murray (D-WA)
- Sen. Sanders (I-VT)
- •Sen. Tester (D-MT)
- •Sen. Wyden (D-OR)
- •Whip Durbin (D-IL)
- •Whip Thune (R-SD)





ADVOCACY FANS & STICKERS









CLOSING THOUGHTS

SCOTT KAUFFMAN

Chair, ALS Association Board of Trustees





2023 ALS ASSOCIATION SPONSORS













2023 ALS ASSOCIATION SPONSORS

Apellis Genentech A Member of the Roche Group



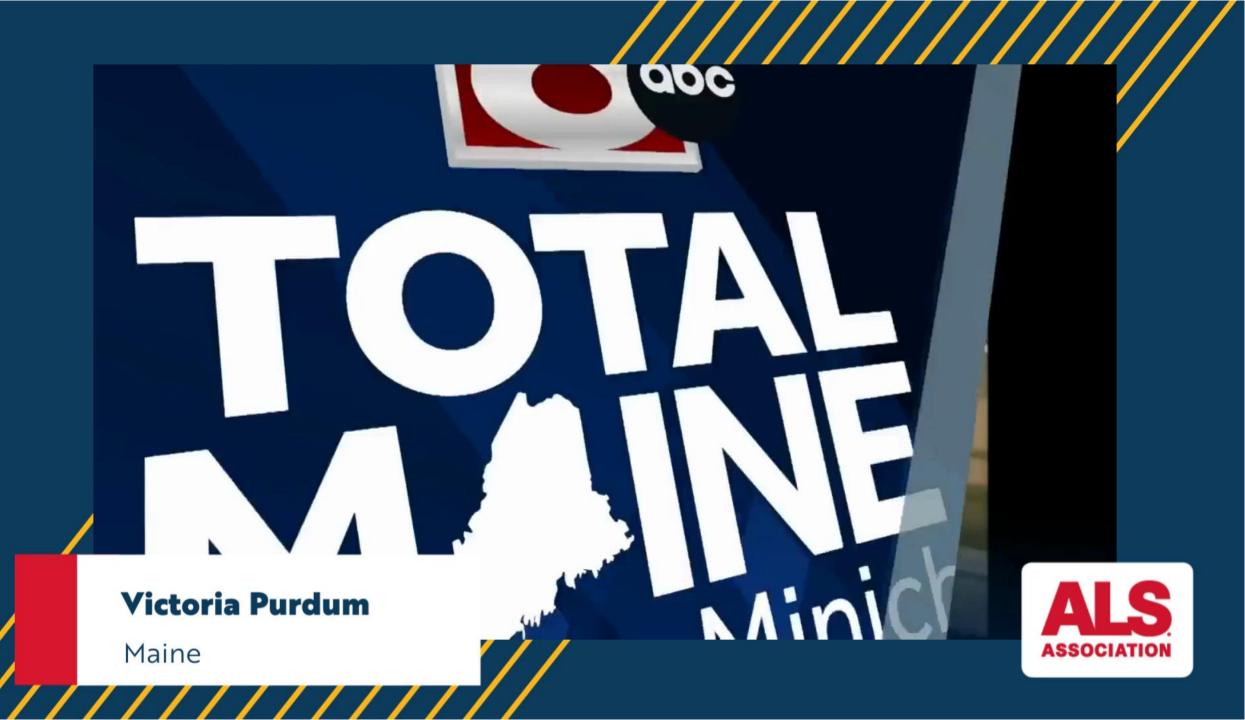








ALS Advocate Victoria Purdum



THANK YOU

FOR YOUR JOINING OUR AUGUST ACTION MONTH KICKOFF!

TAKE ACTION: ALS.ORG/AUGUST



