

Fiscal Year 2021

Annual Report



Year Ending January 31, 2021



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Kathleen Poirier – painter and person living with ALS.



From Our Leadership

We knew that we could not wait for the COVID-19 pandemic to be over to accelerate our vision to create a world without ALS. That is why we are so proud of the work reflected in our fiscal year 2021 report – because it reflects the tenacity of a community that will not stop.

The pandemic created unprecedented challenges to our mission. Due to event cancellations, our chapters faced significant revenue shortfalls that forced many to consider suspending services. Thus, we quickly shifted our focus to mission continuity, making sure that no one affected by ALS would lose access to services. That included quickly transitioning to telehealth opportunities at each of our multidisciplinary care centers to ensure patients would stay current with their physicians and not have to leave the safety of their homes. This new application of an existing communications technology extends to ALS support groups, too.

At the same time, our research program did not wait out the pandemic. Although quarantine rules made some clinical trial sites inaccessible to both researchers and trial participants, we were still able to commit funding for 24 new projects to support promising projects worldwide this year. Despite all the challenges of conducting research this past year, we managed over 162 active projects with a multiyear commitment of over \$55M and \$113M committed to research.

Our work advocating on behalf of people living with ALS also did not stop. While we could not safely advocate in person, we quickly transitioned to online advocacy. Our advocates generated nearly 85,000 messages to members of Congress this year. And they had some big wins, including doubling funding for research at the Department of Defense ALS Research Program and achieving a long-term goal of ending the five-month waiting period for people with ALS to access their Social Security Disability Insurance. Moreover, when Amylyx Pharmaceuticals reported that the promising new drug AMX0035 was shown to be safe and effective in clinical trials, we went into action, gathering more than 50,000 signatures on a petition calling on the company and the FDA to work together to make that drug available to patients as quickly as possible.

That is just some of the great work reflected in this report, which illustrates how the innovations and flexibility this past year not only allowed us to continue serving the community during a pandemic, but also position the organization for sustained success in the years to come.



**Calaneet Balas -
President & CEO**



**Sue Gorman -
Chair, Board of Trustees**



Financial Summary

THE ALS ASSOCIATION HOME OFFICE AND CHAPTERS

The ALS Association continues to utilize support from our generous donors, as well as our reserves, to fulfill our mission throughout the fiscal year. The following unaudited summary reflects Association-wide financial activity for the year that ended January 31, 2021.

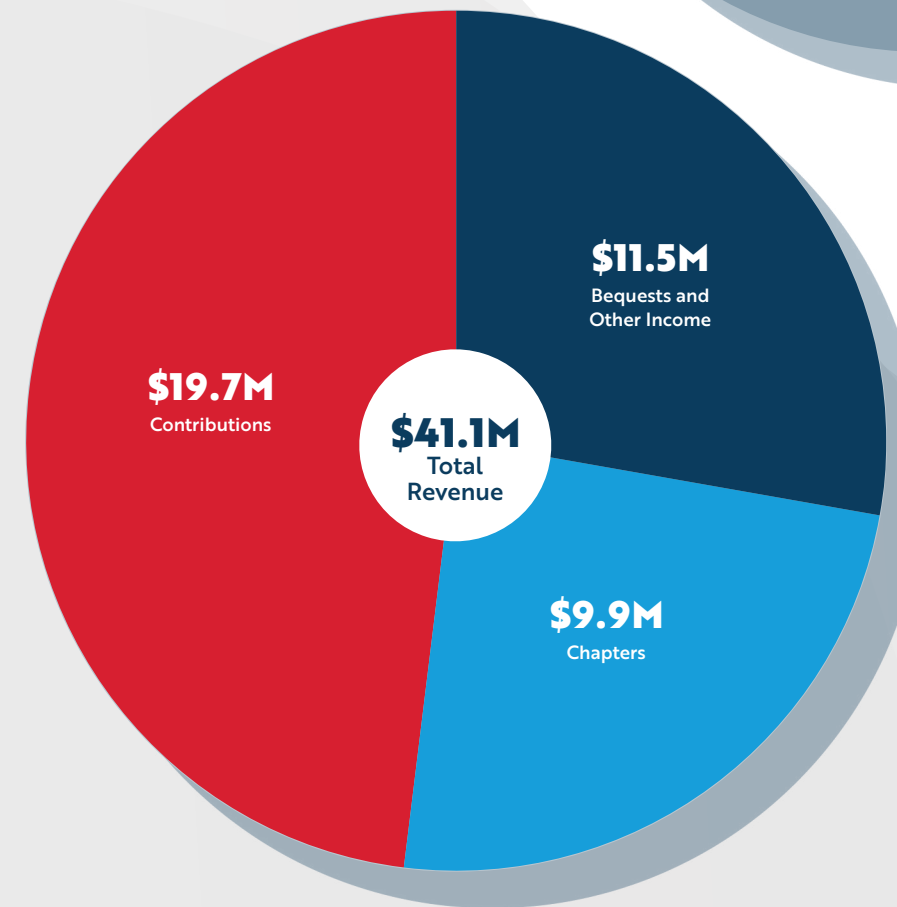
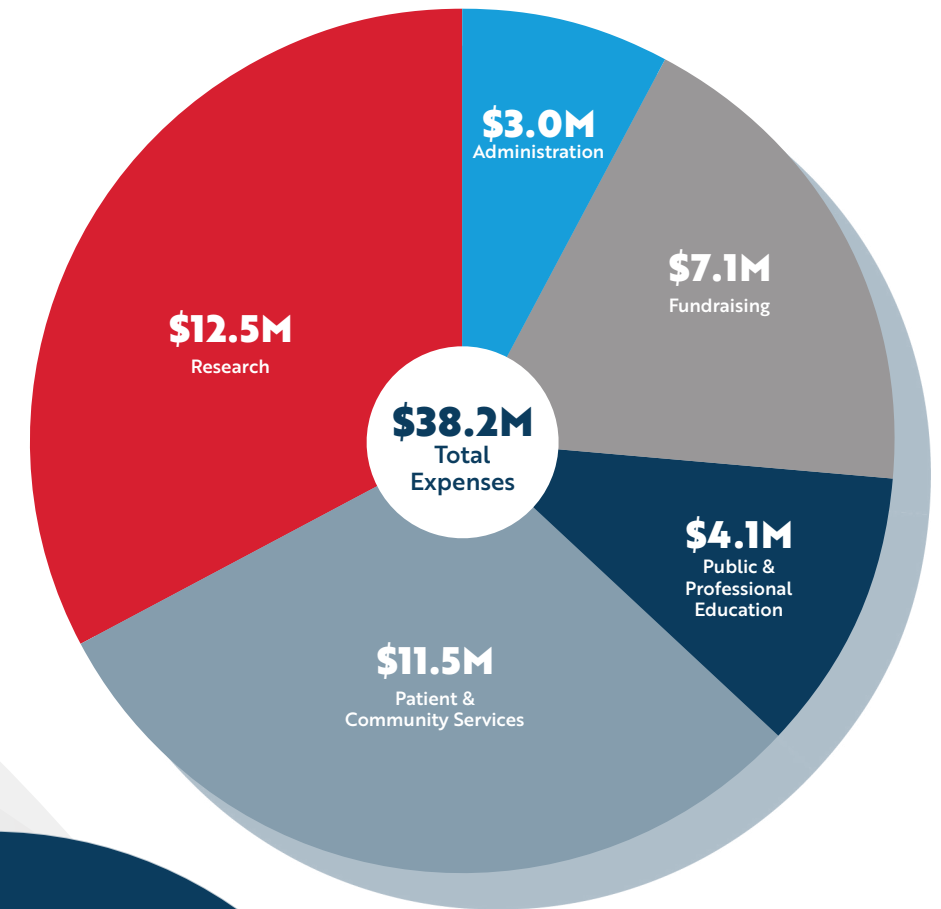


REVENUE AND EXPENSES:	
Total combined revenue	\$97.2 million
Research	\$12.5 million
Other Program Activities	\$56.3 million
Fundraising	\$12.8 million
Administration	\$8.7 million
Total combined expenses	\$90.3 million
Change in net assets	\$6.9 million

ASSETS AND LIABILITIES:	
Total combined assets	\$175.6 million
Total combined liabilities	\$14.3 million
Total combined net assets	\$161.3 million

THE ALS ASSOCIATION HOME OFFICE

Revenue and expenses for the ALS Association Home Office



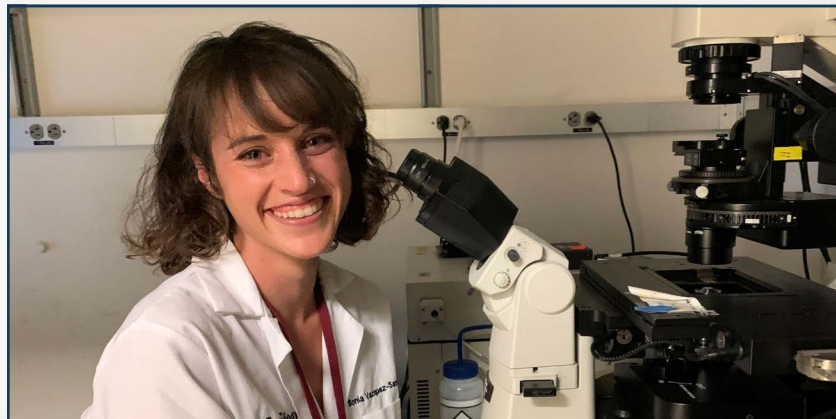


Research

The Search for Better Treatments and A Cure

Despite the challenges posed by the COVID-19 pandemic, The ALS Association committed funding for **24 new projects** to support promising projects worldwide during the 2021 fiscal year. Throughout the year, the Association continued our role as a global leader in ALS research by managing over 162 active projects with a multiyear commitment of over \$55M and \$113M committed to research from the ALS Ice Bucket Challenge.

- There were major advancements in ALS research which will positively impact the landscape of drug development and clinical trials for years to come.
- Research funded by the Association led to the development of a promising new drug from Amylyx Pharmaceuticals. Clinical testing of AMX0035 showed it to be safe and effective at slowing the progression of ALS and helping people live longer. This research was one of the first projects to be funded with monies raised through the ALS Ice Bucket Challenge.
- Our \$3 million commitment to help set up the first-ever ALS platform trial at the Sean M. Healey & AMG Center for ALS is accelerating the rate at which we can test and evaluate treatments. Even in the face of the pandemic, the Healey platform trial is already enrolling clinical trial participants.
- Our partner Biogen published promising results from its phase 1-2 Trial of Antisense Oligonucleotide Tofersen for SOD1 ALS and began enrolling participants for their Phase 3 Valor study. Biogen also announced that there is an open-label extension available in the study, more promising news and hope for people living with ALS.
- We **released the findings from the first ever ALS Focus survey**, illustrating the extent of the financial burden people with ALS and their caregivers face during their ALS journey and the lack of understanding of insurance coverage paying for medical treatments and services. We have also launched a second survey centered around "what matters most" to people with ALS and caregivers.



Funding the Future of ALS Research

The ALS Association continued to support young researchers through the Milton Safenowitz Postdoctoral Fellowship Program for ALS research. During the fiscal year, the Association provided funding for 8 postdoctoral fellows to encourage and facilitate promising scientists to enter the ALS field. The program has proven successful at building up a strong bench of ALS researchers, with more than 75 percent of the awardees staying in ALS research, often going on to establish their own laboratories to continue studying ALS and mentor more ALS researchers along the way.



Mission

Ensuring Mission Delivery During a Pandemic

ALS did not stop in 2020 as the world turned its attention to the COVID-19 pandemic. So neither did we. We dug in our heels and declared that We *Can't Wait* to accelerate research, to provide care to people living with ALS from coast to coast, and to advocate for legislation that empowers our community, regardless of the obstacles created by COVID.

FOCUS ON MISSION CONTINUITY

As a result of the COVID-19 pandemic, people with ALS faced the possibility of losing access to services and their community. Quarantine rules made in-person clinic visits, on-site clinical trials, an in-person community events difficult if not impossible for a community at high risk for respiratory disease. We wanted to make sure that regardless of the economic circumstances from community to community, all people served by the Association would continue to receive the same high standard of care and service.

That is why The ALS Association quickly transitioned activities to virtual platforms. These activities included:

- Online support groups.
- Virtual home visits.
- Online advocacy to continue to fight for better public policies for people affected by ALS.
- Support for telehealth/telemedicine services through our Certified Treatment Centers and Recognized Treatment Centers.

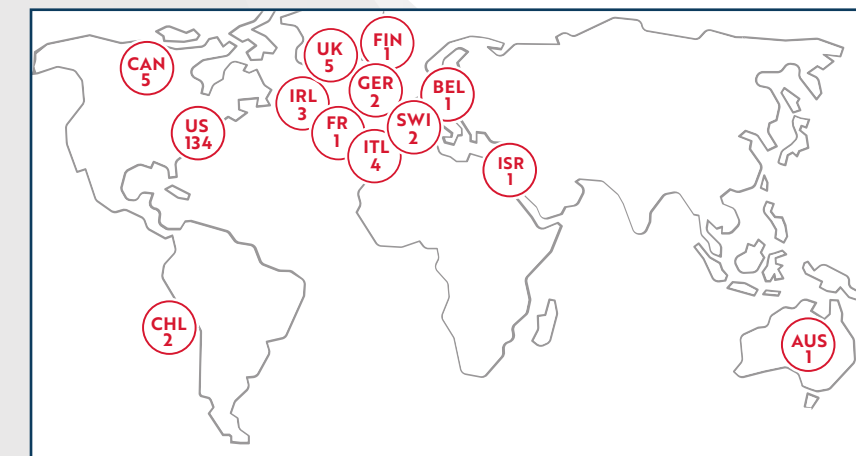
- Care Services staff available by phone and email.

CONTINUING TO LEAD ON RESEARCH

The global pandemic created significant constraints on conducting research around the world. Quarantine rules put in place in response to the pandemic made some clinical trial sites inaccessible to both researchers and to trial participants. Because the pace of research initially slowed, the Association made the decision to limit the issuance of new research grants until more certainty could be obtained regarding the continued impact of the pandemic. Despite these challenges, the Association continued to fund more than 162 research projects around the world and led the push to make a promising treatment available to patients as quickly as possible.



162 research projects around the world





Care Services

Empowering People with ALS to Live Their Best Lives

In fiscal year 2021, The ALS Association's chapter network served more than 21,000 people living with ALS, almost **2,300** of which were military veterans. The ALS Association's Certified Treatment Centers of Excellence and Recognized Treatment Centers served **9,296** people living with ALS, and more than **\$4.8 million** in grants were provided through our Certified Center Program.

In response to the COVID-19 pandemic, our mission quickly pivoted to sustain our high standard of care for the ALS community in the face of quarantines. This meant working with our clinic network to support telehealth access for patients when appropriate and helping our network establish effective virtual support for the people we serve.

Additionally, educational resources were accessed by over **42,000** people

resulting in **27,175** website views, **7,510** downloads, and **557** online orders accessed on Association Care Services website pages. These resources included:

- Twelve Living with ALS and Families resource guides available in digital and print formats and translated into Spanish to help educate people about challenges that living with ALS can cause
- Twelve archived webinars, viewed **2,397** times live or on-demand
- ALS medical information packets and materials including ID cards and eye gaze charts.

To ensure people with ALS receive the best care from ALS Association Certified Centers, in FY2021:

- We supported **73** ALS Association Certified Treatment Centers of Excellence and **21** Recognized Treatment Centers providing multidisciplinary care incorporating best practices as established by the American Academy of Neurology along with **90+** Affiliated Clinic partnerships throughout the US.
- **25,831** people attended support groups offered through our vast U.S. chapter network including people with ALS, caregivers, family members, and health care professionals.



Helping People Affected by ALS Continue Their Education

The ALS Association awarded \$270,000 to 94 students from 35 states this year through the Jane Calmes ALS Scholarship Fund. The fund provides up to \$5,000 per year to students who faced the devastating financial burden of ALS. Established by Mark Calmes, of The ALS Association's National Board of Trustees, the fund is named in honor of his late wife, Jane, who fought ALS for eight years and passed away in August 2017. "Until we can meet 100 percent of the need, I will always have a feeling of sadness and futility for those we could not help." — Mark Calmes



Advocacy

Fighting for Research Dollars and Access to Health Care

During the 2021 fiscal year, The ALS Association's more than 40,000 advocates generated nearly **85,000 messages** to members of Congress. In response to the COVID-19 pandemic, we transformed our annual Advocacy Fly-In and National Advocacy Conference to virtual events. Our advocates completed over 630 meetings and over 500 calls with members of Congress. Those efforts paid off by convincing lawmakers to enact policies that will enhance the lives of people living with ALS while also accelerating the search for treatments and a cure.

During FY2021, ALS advocates were able to double appropriations for Department of Defense's ALS Research Program from \$20 million to **\$40 million** to find treatments and a cure for ALS.

We also achieved a longstanding goal when Congress passed the ALS Disability Insurance Access Act, thereby waiving a five-month waiting period for Social Security Disability benefits for people living with ALS.

We also launched a petition calling on the FDA and Amylyx Pharmaceuticals to work together to speed up the process of getting AMX0035 — a drug shown to be safe and effective in clinical trials — available for people living with ALS as quickly as possible. More than 50,000 people signed the petition.

At the beginning of the COVID-19 pandemic, we endorsed legislation to expand access to telehealth and worked with the Centers for Medicare and Medicaid to make sure that health care services that are key to the ALS community related to speech and swallowing were covered for telehealth.

The ALS Association also achieved a longstanding goal when Congress passed the ALS Disability Insurance Access Act, thereby waiving a five-month waiting period for Social Security Disability benefits for people living with ALS.

ALS ASSOCIATION The ALS Disability Insurance Access Act

The ALS Disability Insurance Access Act will eliminate the current five-month Social Security Disability Insurance (SSDI) waiting period for people living with ALS.

ALS advocates across the country have worked tirelessly with Congress to pass this bill!

2016		2019	
The ALS Disability Insurance Access Act (S. 2904 and H.R. 5183) is introduced on May 9, 2016	S. 379 and H.R. 1171 Reintroduced in the 115th Congress	S. 578 and H.R. 1407 Reintroduced in the 116th Congress	The ALS Disability Insurance Access Act Passes
	2017		2020

To learn more, visit www.als.org/advocacy



Community Impact

Growing support for the fight

THE WALK TO DEFEAT ALS®

Across the country the ALS community came together to hold more than **173** walks with their local ALS Association chapters, raising **\$18,145,390** to advance our mission to find treatments and a cure for ALS.



TEAM CHALLENGE ALS

In 2020 the Association's Team Challenge ALS program continued to spread across the country as participants in endurance challenges including marathons, cycling, obstacle courses, and winter sports events came together to combine their passions with a commitment to join the fight. Team Challenge raised **\$2,594,078** with **42 events**.



DISTINGUISHED EVENTS

- Total funds raised was \$4,554,705
- Includes Golf, Gala, other ticketed events and the CEO Soak.



“Seeing all the other teams, families, and friends battling the same thing we are and making the most of it and getting something positive out of something so incredibly awful was amazing. It made us more aware of what’s available and just how much support there is out there for us and the ALS community.”

— Gina Unruh, Oregon and SW Washington Chapter



Our Impact

Serving, advocating for, and empowering people with ALS to live their lives to the fullest

\$113 million

dedicated to research since the ALS Ice Bucket Challenge to advance treatments and a cure



21,545 people living with ALS served through the chapter network in the past year

\$4,885,387

in grants provided through our Certified Center Program



162

Active research projects across 13 countries



\$40 Million

Boosted funding for the ALS Research Program at the Department of Defense (DOD) from \$20 to \$40 million in 2020 to support the creation of more clinical trials that will lead to the discovery of treatments and a cure.



Ended the SSDI 5-month waiting period for people living with ALS

8

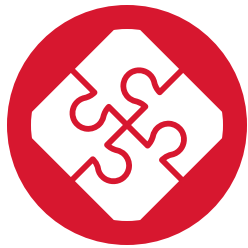
new postdoctoral fellows chosen in 2020

2,295

veterans received assistance through our nationwide chapter network

25,831

attendees at support groups offered through our vast chapter network across the U.S.



Corporate Partners

The ALS Association appreciates the generosity of the many national partners we work with, and we are delighted to recognize them for their support of our research, services, and advocacy efforts this year. We appreciate your continued work to help move our mission forward in the fight against ALS.

PERMOBIL FOUNDATION

Permobil has been committed to helping people with various functional disabilities for more than 50 years and is the longest standing national partner of The ALS Association. Since the inception of our partnership in 2006, they have contributed over \$1.6 million to advance the Association's mission through direct cash sponsorships to support national programs, such as the Walk to Defeat ALS®, National ALS Advocacy and Clinical Conferences, direct chapter sponsorship support, and in-kind support through donations of seat elevators to people living with ALS.

MITSUBISHI TANABE PHARMA AMERICA

Mitsubishi Tanabe Pharma America became a national corporate partner in 2016 with a premier sponsorship of the Walk to Defeat ALS® program, providing support to cutting-edge research, nationwide advocacy efforts, and care service programs for people with ALS and their families. Contributing over \$1.5 million, they continue to support the mission through additional funding for national programs. In addition, they continue

to fund the Mitsubishi Tanabe Pharma Care Grant established in 2018 enabling the Association to award grants for the expansion and implementation of new and current care services programs.

CYTOKINETICS

Cytokinetics is dedicated to changing the progression of ALS, demonstrating this every day through their work to develop a treatment for ALS. They have been a long-time partner of the Association and their generosity has resulted in over \$1 million, contributed at local and national levels, supporting Association programs, research, and care services.

NUMOTION FOUNDATION

Numotion is committed to its leadership as the nation's leading provider of Complex Rehab Technology and became a national partner of the Association in 2013. Since then, Numotion has contributed over \$1.6 million to advance the Association's mission through direct cash sponsorships to support national programs, direct chapter sponsorship support, and in-kind donations of their products. They now lead the effort as a premier Walk to Defeat ALS® partner.

BIOHAVEN PHARMACEUTICALS

Biohaven Pharmaceuticals is a clinical-stage biopharmaceutical company with proven leadership in industry and academic settings. An ALS Association partner since 2017, Biohaven has contributed over \$300,000 through direct cash contributions to support national programs, direct chapter support, and in-kind donations of products, continuing their support to help improve the lives of those living with ALS and their families.

HARRIS TEETER

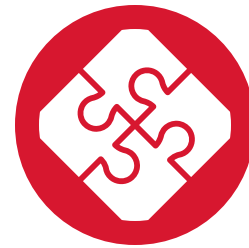
Harris Teeter, a wholly owned subsidiary of The Kroger Co. (NYSE: KR), was co-founded in 1960 by North Carolina grocers W.T. Harris and Willis Teeter. Operating over 230 stores and 14 fuel centers in seven states and the District of Columbia, they are headquartered in Matthews, NC with approximately 30,000 associates. A partner since 2017, Harris Teeter employees have contributed over \$150,000 through the Harris Teeter's Community Cares Associate Giving Program. In addition, they have supported the Association through in-kind donations of products that enhance our mission to support people living with ALS and their families.

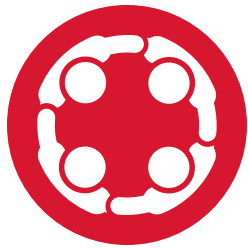
BIOGEN PHARMACEUTICALS

Biogen is a multinational biotechnology company specializing in the discovery, development, and delivery of therapies for the treatment of neurological diseases to patients worldwide. Their participation as a partner has enabled additional support in ALS advocacy and understanding how to better serve the ALS community. Thanks to their over \$500,000 investment in Association programs since 2013 Biogen has helped us expand our mission programs.

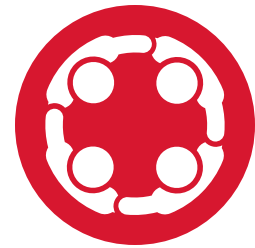
IONIS PHARMACEUTICALS

Ionis focuses on innovation in RNA-targeted therapeutics. Their antisense technology platform has served as a springboard for drug discovery and realized hope for patients with unmet needs. They also partner with other biotechnology companies like Biogen to bring more efficient trials to the ALS community. Their participation as a partner supporting mission programs like ALS Roundtables and ALS Focus help us better serve the ALS community.





Board of Trustees



We are proud to acknowledge the following members of the ALS National Board of Trustees (February 1, 2020 - January 31, 2021):

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1913 – 2012



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