

ALS
ASSOCIATION



Annual Report

FY2022

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**Making ALS livable
for everyone,
everywhere until
we can cure it.**

Sincerely, Leadership

“This is what it takes. We are stronger as one—One team. One mission. One world without ALS.”

Doing whatever it takes to attain an audacious goal requires bold, transformative action and the collective effort and singular focus of one team working together to achieve one goal. This year, we made a promise to our community to transform ALS into a livable disease. That means people diagnosed with ALS live longer lives and that they are empowered to live life as they want—with greater engagement and autonomy. It also means we are finding ways to prevent our loved ones from getting the disease. It means doing whatever it takes to find new treatments and cures, to optimize current treatments and care and making sure everyone has access to the care and assistive technology they need, regardless of where they live.

We can only make good on that commitment by marshalling all the resources available to us and aligning behind a single mission, as one team. That is why we made the decision this year to create a unified structure for our organization, which will enhance the depth and breadth of the care we provide and increase the resources available to optimize that care for people living with ALS all across the country. While it is important that as we go through the process of becoming one team with one mission, our highest priority remains our work supporting people with ALS and their families.



Calaneet Balas
President & CEO



Sue Gorman
Association Chair

Our Mission

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 Vision

Create a world without ALS.

Core Values

COMPASSION - INTEGRITY - URGENCY

Our Mission

This year we launched a strategic goal of making ALS a livable disease and made the commitment to do Whatever it Takes to achieve that goal and fundamentally transform the lives of people living with the disease.



Our goal: Make ALS a livable disease.

What This Means

Longer Lives

- Life-extending treatments made accessible to ALL people with ALS
- Prevention of harms associated with ALS

Improved Quality of Life

- People with ALS empowered to live their lives as they want
- Greater engagement and autonomy
- Reduced or prevented physical, emotional and financial burdens

Preventing Loved Ones from Getting ALS

- Genetic screening to identify those at risk
- Prevention of new cases of ALS

How We Get There

Find New Treatments & Cures

- More clinical trials and participation with research
- More focused research

Optimize Current Treatments & Care

- Improve and deliver state of the art care
- Improve assistive technology

Prevent or Delay Harms Associated with ALS

- Identify risk factors
- Treat as early as possible
- Discover new preventative treatments

Ensure Access & Prevention

Ensure people with ALS have access to effective treatments, and cases of ALS are being prevented.

Empower & Engage

Empower people with ALS to engage with the world in the way they want.

Reduce Burdens

Reduce the physical, emotional and financial burdens of living with ALS.

Ensure Support For All

Ensure ALL people with ALS and their caregivers receive high quality services that benefit them.

Create Accountability

Create a culture of accountability to ensure meaningful impacts for people with ALS.

Our Impact

ADVOCACY



Mobilized ALS advocates and Congress to pass the ACT for ALS Act to speed the discovery of new treatments for people living with ALS through more clinical trials and expanded access to investigational drugs.



Galvanized ALS advocates to push for increased federal dollars for ALS research at the Department of Defense, new funding for clinical trials at FDA, and continued funding for the National ALS Registry.



Advocated to boost funding for the National Institutes of Health, resulting in an estimated **\$115 million in funding for ALS research** in fiscal year 2022.



Preserved protections for pre-existing conditions for people living with ALS in collaboration with other leading patient advocacy groups.



CARE SERVICES



21,645 people living with ALS served through the chapter network.



8,515 people viewed, downloaded, or ordered our educational materials including the Living with ALS and Families and ALS resource guides and medical information packets.



2,081 veterans received assistance through our nationwide care network.



9,586 people registered with our nationwide care network and served through our Certified Treatment Centers of Excellence & Recognized Treatment Centers.



\$4,831,102 in grants provided to our Certified and Recognized Treatment Centers to support clinic operations including equipment, staffing and continuing education.



\$500K in higher educational scholarships was awarded to 100 students through the Jane Calmes Scholarship Fund

Fighting for Research Dollars and Access to Health Care



This past year, we empowered advocates across the country to send more than **41,000 messages** to members of Congress and hold more than **530 meetings** with lawmakers in pursuit of public policies that will speed up the search for treatments and a cure, optimize the care available today and enhance the lives of people living with ALS.

We led a campaign to encourage the FDA to act with urgency and flexibility to make **AMX0035** (now known as **RELYVRIO**) available for people living with ALS. In May, we convened a meeting between the agency and people living with ALS to deliver the message that *We Can't Wait* for additional clinical trials when the evidence already demonstrated the therapy to be safe and effective. And when Amylyx filed its new drug application for approval, we swiftly called on the agency to conduct a priority review.

We also led the successful fight for enactment of the **ACT for ALS**, legislation that supports access to experimental treatments and provides the FDA additional research capacity and public/private partnerships to speed development and approval of new treatments.

In addition, we fought to preserve protections for pre-existing conditions for people living with ALS in collaboration with other leading patient advocacy groups. Urged governors to support people living with ALS and their families with access to care through telehealth and COVID-19 vaccine prioritization. Advocated to boost funding for the National Institutes of Health, resulting in an estimated **\$115 million** in funding for ALS research in fiscal year 2022. And galvanized ALS advocates to push for increased federal dollars for ALS research at the Department of Defense, new funding for clinical trials at FDA, and continued funding for the National ALS Registry.

Empowering people with ALS to live their best lives

This past year our care services teams in communities throughout the country served more than **21,000** people living with ALS, including more than **2,000 veterans**.

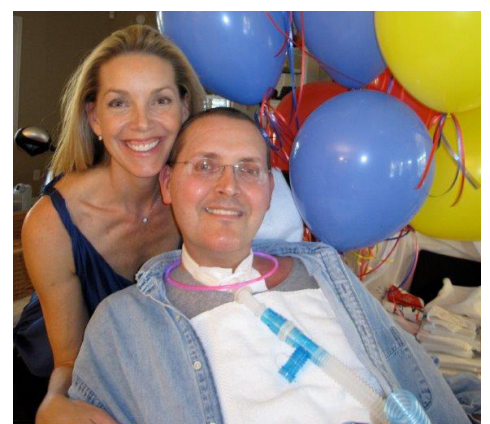
We provided **\$4.8 million** to our nationwide network of Certified Treatment Centers of Excellence and Recognized Treatment Centers, providing care shown to extend and enhance the quality of life to **9,586** people living with ALS.

As part of our effort to expand access to multidisciplinary ALS care, we teamed up with the Veterans Administration to increase the number of Veterans Health Administration clinics designated as Certified Treatment Centers of Excellence or Recognized Treatment Centers to make sure health care professionals are providing the best possible care available, we provided 12 online, on-demand, education webinars for professionals interested in learning more about ALS treatment and care.

All were offered **free of charge** and approved for continuing education credits for nurses, social workers and allied health professionals.

We also conducted three new **ALS Focus** surveys covering caregiver needs, telehealth and mobility challenges to learn directly from the community what their needs are and how to tailor programs and services to be responsive to those needs in real time. There are already more than **2,200** members participating in ALS Focus.

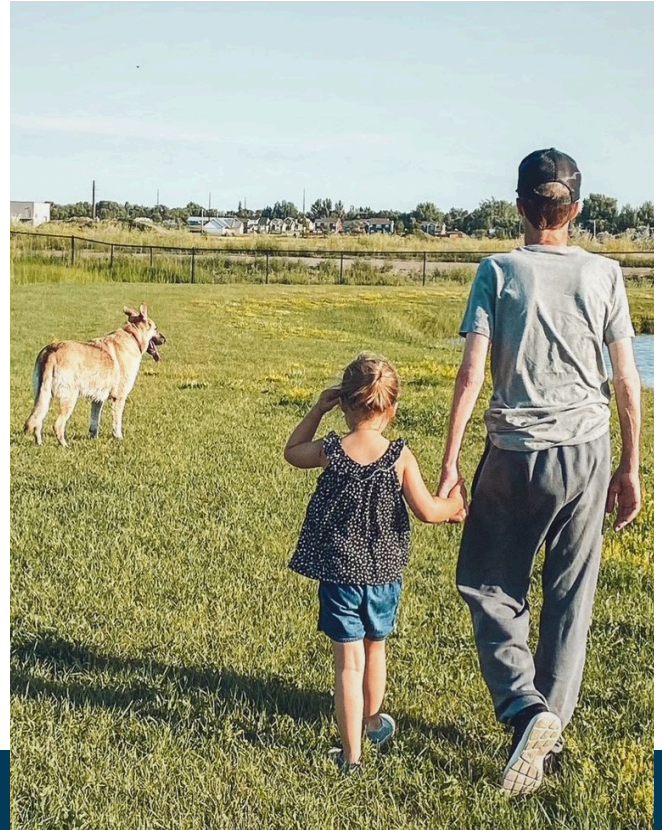
Through the **Jane Calmes ALS Scholarship Fund**, which was established in 2019 to provide \$5,000 for students directly impacted by ALS, the Association awarded **100** scholarships for the 2021-2022 school year totaling **\$500,000**. Since its inception, this scholarship program has awarded 239 scholarships equaling **\$1,195,000**.



Searching for *Better Treatments and A Cure*

The ALS Association committed funding for **28 new projects** around the world, with a total commitment of **\$9.5 million**. Including previous commitments, the Association provided **\$10.1 million** to **72 projects** during the fiscal year.

When our commitment to research leads to promising new treatments, we immediately begin the work of making those treatments available to the community. Throughout the year, we worked tirelessly to bring **AMX0035** (now known as **RELYVRIO**), a promising new drug shown to extend life and slow disease progression, to people living with ALS. The FDA recently approved Amylyx's New Drug Application for the treatment, and we continue to push to make RELYVRIO available for the ALS community.



RESEARCH



Healey platform trial progresses at super speed

We committed \$3M to co-fund the first ever platform trial in ALS. Enrollment has progressed 3 times faster than normal and is now complete for the first 4 investigational treatments with first data expected in mid-2022.



Reducing time to diagnosis is key to ALS

We created a new diagnostic guide, thinkALS, that will help neurologist more quickly diagnose ALS. Earlier diagnosis allows people with ALS to participate in clinical trials and access treatments sooner, as well as receive care services support. Check out this new tool at www.als.org/thinkals.



Bringing effective treatments closer to approval

Including RELYVRIO from Amylyx Pharmaceuticals that was shown to extend life and slow disease progression, and continued progress on tofersen, a genetic therapy for SOD1-ALS in late phase trials, along with progress on biomarker research.



Finding out what matters most to people with ALS and their caregivers

Since launching, over 2,100 are members in ALS Focus. These surveys bring the perspectives and needs of people with ALS and caregivers to the forefront of program and policy decision making. To join, visit www.als.org/research/als-focus.



4 new fellows

Milton Safenowitz Postdoctoral Fellowship Program

\$9.5M

spent to fund 28 new projects around the world

Other promising developments from research we supported include:

- Identifying the first compound (NU-9) that eliminates the ongoing degeneration of diseased upper motor neurons, a key contributor to ALS.
- The announcement by Ionis Pharmaceuticals of FUSION, of a Phase 3 clinical trial of ION363 (also known as jacifusen), a novel antisense oligonucleotide (ASO) for ALS patients with a mutation in the fused in sarcoma (FUS) gene.
- We launched a new grant funding program to support early-stage clinical trials. In addition, our [Milton Safenowitz Postdoctoral Fellowship Program](#) welcomed **4 new fellows** to the only program of its kind, specifically funding early ALS postdoctoral fellows who are working eagerly to understand the disease biology and searching for a cure. Our Lawrence & Isabel Barnett Drug Development Program awarded close to **\$3 million to 6 projects** to invest in bringing potential treatments into clinical trials.

In addition, we created new resources to help speed up the time to diagnosis and to expand the drug development pipeline.

- We launched **thinkALS**, an early diagnosis guide targeting general neurologists to help them easily identify ALS symptoms and refer their patients to multidisciplinary ALS centers as quickly as possible.
- We also launched a genetic counseling and genetic testing education campaign to inform people with ALS and their families about the benefits and costs of genetic testing. In order for people living with ALS and their families to make informed decisions about genetic testing, they must have access to current education about clinical genetics in ALS and safeguards against genetic discrimination.

Growing Support for the Fight



169

Walk to Defeat ALS® events held across the country, raising

\$19.6M



60

Golf, Gala, and CEO Soak events hosted, raising

\$6.7M



31

Team Challenge ALS endurance events held, raising

\$2.6M

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.

\$250K+ Partners:



Mitsubishi Tanabe Pharma
America

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 towards cutting-edge research, nationwide advocacy efforts, and care service programs for people with ALS and their families. Contributing over \$3 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.



BIOPEN 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 \$1M investment in Association programs since 2013 Biogen has helped us expand our mission programs.



\$100K+ Partners:



Board of Trustees

We are proud to acknowledge the following members of the ALS National Board of Trustees:

Lawrence R. Barnett

Founding Chairman
(deceased)

Sue Gorman

Association Chair
Professional interior
designer/principal
Sue Gorman Interior
Designs
Charlotte, North Carolina

Scott Kauffman

Association Chair-Elect
Chairman & CEO
MDC Partners
New York, New York/Palo
Alto, California

Fred DeGrandis

Association Vice-Chair
Senior Director and
President
Medic Management LLC
and NorthShore
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Connie Houston

Association Treasurer
Vice President, Finance
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Keith Gary, Ph.D.

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Jinsy Andrews, MD, MSc.

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Pennsylvania

John P. Krave, Esq.

Association Trustee
Senior Counsel
Kaiser Foundation
Hospitals
Pasadena, California

Nancy LeaMond

Association Trustee
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Engagement Office/
Executive Vice President,
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Center
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Association Trustee
Professor of Political
Science
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Davidson, North Carolina

Warren Nelson

Association Trustee
President and Chief
Financial Officer
JEM Restaurant Group
Palm Harbor, Florida

Sandra (Sandy) Piersol

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Corporate Compliance
Officer
McBee, division of
Netsmart Tech
Wayne, Pennsylvania

Judith A. Pratt, D.M.D

Association Trustee
Doctor of Dental Medicine
& Owner
Pratt Family Dentistry
East Greenwich, Rhode
Island

**Charles J. Robinson,
D.Sc., P.E.**

Association Trustee
Director, Center for
Rehabilitation Engineering
Chair Professor
Department of Electrical
Computer Engineering
Clarkson University
Potsdam, New York

John Robinson, Ed.D.

Association Trustee
Retired U.S. Army
Parrish, Florida

David Van de Riet

Association Trustee
Vice President,
Investments
Raymond James &
Associates
St. Louis, Missouri

Wendy J. Schriber, Esq.

Association Trustee
Retired Partner
Proskauer Rose LLP
New York, New York

Kevin Spinella, Esq.

Association Trustee
Attorney
Goodwin
Washington, DC

Mark Stancil

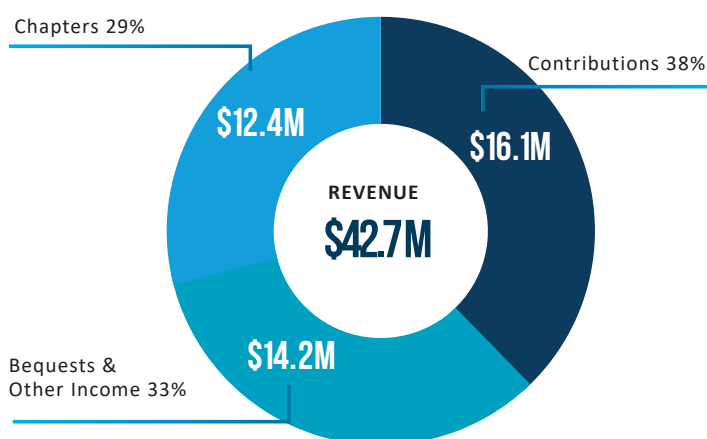
Association Trustee
Vice President
Goldman Sachs
Marietta, Georgia

Financial Summary

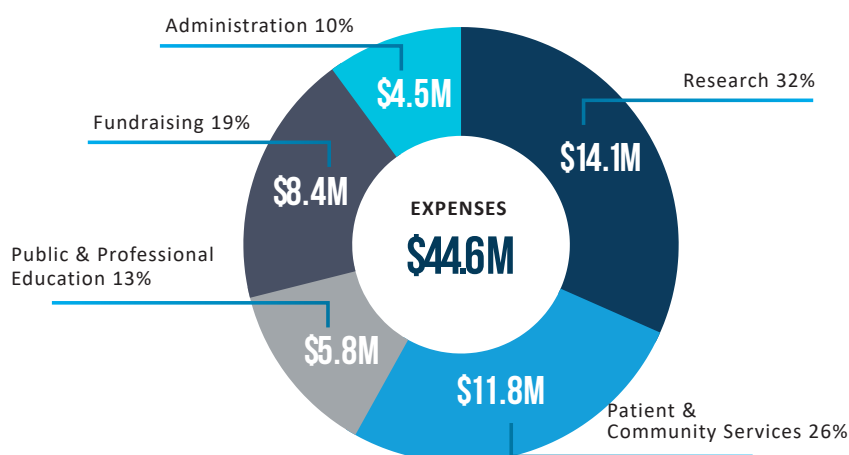
The ALS Association continues to utilize support from our generous donors, as well as our reserves, to fulfill our mission throughout the fiscal year. The following unaudited summary reflects Association-wide financial activity for the year that ended January 31, 2021.

The ALS Association Home Office

REVENUE



EXPENSES



The ALS Association Home Office and Chapters

REVENUE

Total Combined Revenue \$108.0M

EXPENSES

| | |
|--------------------------------|----------------|
| Research | \$14.1M |
| Other Program Activities | \$59.0M |
| Fundraising | \$15.5M |
| Administration | \$10.2M |
| Total Combined Expenses | \$98.8M |

ASSETS

Change in Net Assets \$9.2M

| | |
|----------------------------------|-----------------|
| Total Combined Assets | \$185.7M |
| Total Combined Liabilities | \$14.0M |
| Total Combined Net Assets | \$171.7M |



The ALS Association
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