



2020

ANNUAL REPORT



YEAR ENDING JAN. 31, 2020



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OUR VISION:
A WORLD
WITHOUT ALS

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 IMPACT

**\$111
MILLION**



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



**SPEARHEADED THE EFFORT
TO PASS THE BIPARTISAN
ALS DISABILITY INSURANCE
ACCESS ACT**

*to waive the 5-month wait
for people living with ALS.
As of December 2019, 220
Representatives and 50
Senators support the bill.*



\$3 MILLION

*The ALS Association
invested in Healey ALS
platform trial to accelerate
drug development*



20,125

*people living with ALS
served through the
chapter network in the
past year*



\$20 MILLION

*Initiated and led campaign
to increase funding for the
ALS Research Program at the
Department of Defense (DOD) to
\$20M in fiscal year 2020 — a \$10M
increase over the funding levels in
previous years*



2,400+

*veterans received
assistance through
our nationwide
chapter network*

\$4,995,832

*in grants
provided
through our
Certified Center
Program*



25,588

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





LEADERSHIP

OUR LEADERSHIP

This past year was pivotal in the fight to build a world without ALS as the Association reflected back on the progress made since the Ice Bucket Challenge. The viral sensation truly changed the future of ALS and we turned our collective attention to the work ahead with a simple yet powerful phrase: Challenge Me.

It is hard to believe more than five years have passed since the world drew inspiration from Pete Frates, Pat Quinn, and Anthony Senerchia, helping to raise more than \$220 million for ALS organizations around the world. Reflecting back on where we have come since then, we were proud to share an independent report this year showing how the outpouring of support allowed us to increase our annual research funding around the world by 187 percent, and to nearly double our nationwide network of multidisciplinary care centers. That means more researchers are collaborating than ever before, more clinical trials are moving forward, and more people are receiving the critical care they need.

We again turned to Pete and Pat remembering their late friend, Anthony, who called on everyone in the ALS community to bring the same level of urgency to the fight every day with two simple words: Challenge Me. Challenge me to participate, to advocate, and to donate. In 2019, the Association's more than 20,000 advocates rose to the challenge by generating nearly 73,000 messages to members of Congress and completing over 700 meetings with members of Congress on our National Advocacy Day, fighting for the critical needs of the ALS community nationwide. Sadly, we lost Pete shortly after issuing this call to action, but the impact of his legacy continues.

Our care services team challenged itself by serving more than 20,000 people living with ALS, providing equipment loans, education, and support to those in need. We also launched a new scholarship program to help students affected by ALS, so they see their education goals come to fruition by easing some of the financial burden caused to families.

We continue to work with our many partners both here and abroad, and we are forever grateful to the dedication and support of all our stakeholders who continue to play a crucial role in the fight to end ALS. Together we will lead the way in research, care services, public education, and public policy — giving help and hope to those facing this disease.

Because ALS doesn't stop and neither do we.

Very Best Regards,

Calaneet Balas, President & CEO

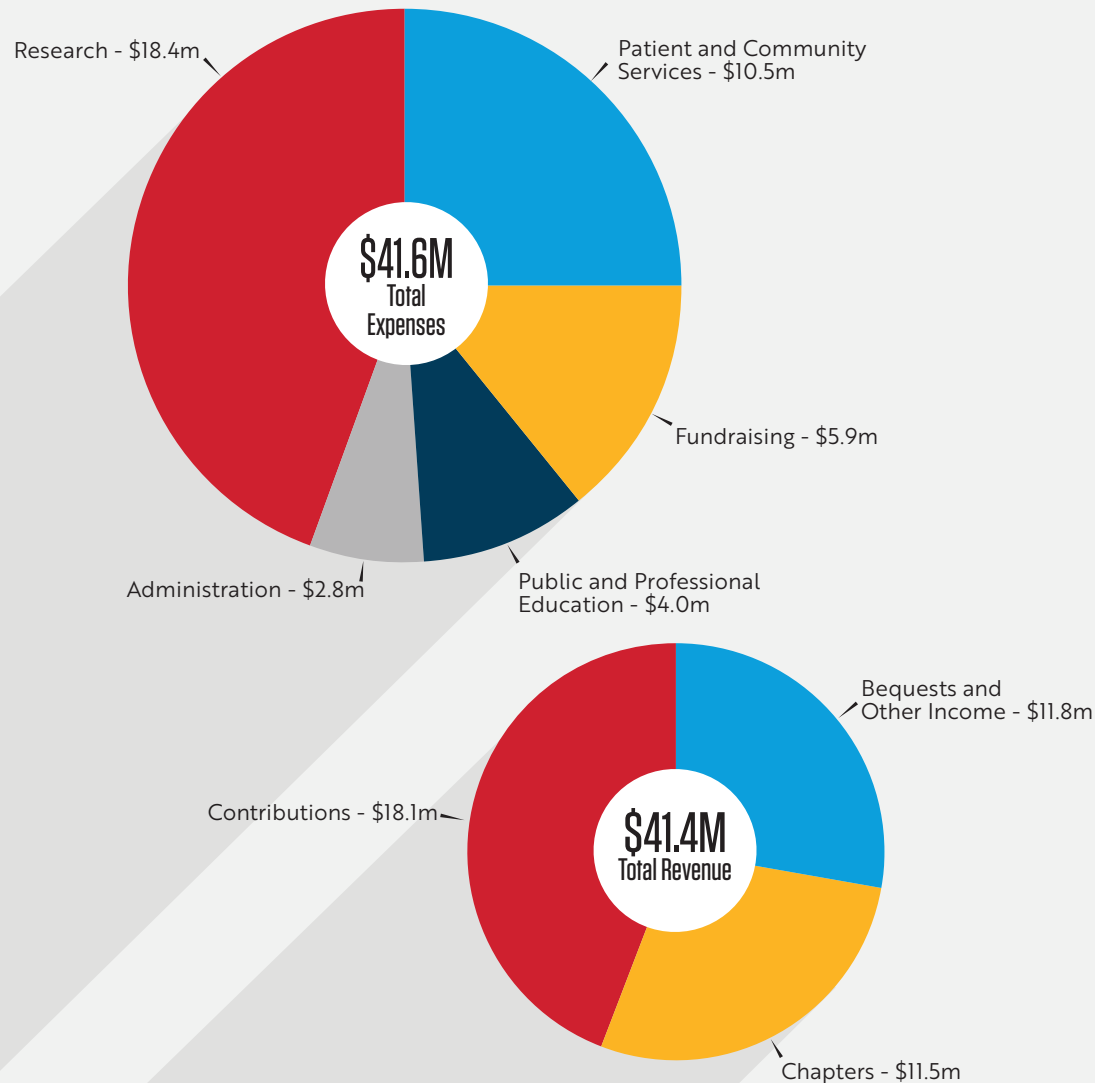
Sue Gorman, Chair, The ALS Association Board of Trustees





FY20 FINANCIAL SUMMARY

THE ALS ASSOCIATION NATIONAL OFFICE



THE ALS ASSOCIATION NATIONAL 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, 2020.

REVENUE AND EXPENSES

Total combined revenue	\$105.0 million
Research	\$18.4 million
Other Program Activities	\$60.7 million
Fundraising	\$14.2 million
Administration	\$8.0 million
Total combined expenses	\$101.3 million
Change in net assets	\$3.7 million

ASSETS AND LIABILITIES

Total combined assets	\$166.0 million
Total combined liabilities	\$11.6 million
Total combined net assets	\$154.4 million



THE SEARCH FOR BETTER TREATMENTS AND A CURE

During the 2020 fiscal year, The ALS Association committed **\$21.5 million** to support promising projects worldwide, funding **70 new projects** in **8 countries** and continuing our role as a global leader in ALS research.

There were major advancements in ALS research which will positively impact the landscape of drug development and clinical trials for years to come.

- The Healey ALS Platform Trial, first ever platform trial in ALS, was launched to reduce time and costs related to ALS efficacy trials and increase patient access and participation. The Association invested \$3M in this groundbreaking study.
- The Association teamed up with TargetALS funding a biomarker initiative to develop assays to measure TDP43, the protein that becomes dysfunctional in most cases of ALS. Development of improved assays that can accurately measure and quantify TDP-43 in human biofluids will have a tremendous impact on clinical research and therapeutic development.
- A global, centralized, cloud-based repository of ALS genetic data is being assembled with support from the Association, the first of its kind. The repository will store data in the cloud allowing researchers around the world access to a wealth of sequencing data to study ALS genetics without the infrastructure previously needed. The \$3.3 million grant from the Association will fund cloud storage, computing, and genomic sequencing of 3,000 people living with ALS.



COLLABORATING FOR A CURE

The ALS Association, ALS Finding a Cure, and MDA jointly awarded a clinical trial grant of more than \$2.5 million to expand the first-in-human study that demonstrated promising results leveraging patients' own immune cells to treat ALS. The project is led by investigators at the Houston Methodist Neurological Institute and Massachusetts General Hospital supporting Dr. Stanley Appel and his team.





NEW PROGRAMS TO INCREASE MISSION IMPACT

The ALS Association made significant strides toward expanding cross mission programs to prioritize and elevate the needs and preferences of people with ALS and their caregivers. Two initiatives have been particularly key to mission program development and impact.

ALS FOCUS SURVEY PROGRAM



- ALS Focus is a patient- and caregiver-led survey program that asks people with ALS and current and past caregivers about their needs and burdens.
- The program launched in fall 2019 with the formation of a steering committee representing the drug development industry, academia, government, and people with ALS and caregivers and the Patient and Caregiver Advisory Committee (PCAC), leaders in the ALS community.
- The goal is to learn more about individual experiences to strengthen care for people with ALS and caregivers, accelerate therapy development, improve clinical trials, influence policy makers, and more. Information collected is de-identified and shared free of charge, providing the Association, global researchers, and other organizations working on ALS with accurate information on the disease journey.



ALS ROUNDTABLE PROGRAM



- Launched in spring 2019, the Roundtable Program provides a forum for solution-based discussions with ALS stakeholders, including corporate sponsors, clinician and research leaders, regulatory officials, Association leadership, and most importantly, people with ALS and their caregivers. The goal is to accelerate the development of meaningful treatments for ALS and improve the lives of people living with the disease and their caregivers.
- The Association convened its first roundtable meeting in March 2019. The purpose was to provide input to the Association on setting its strategic priorities for the next three to five years and help define best use of resources to support people living with ALS now and in the future.
- The second Roundtable was held in October, focusing on strategies to ensure any new treatments are accessible and affordable to all people with ALS. Panels and a facilitated group discussion centered around identifying challenges, potential solutions, and action steps to prepare the ALS community for the advent of new drugs to treat the disease.



EMPOWERING PEOPLE WITH ALS TO LIVE THEIR BEST LIVES

In fiscal year 2020, The ALS Association's chapter network served more than 20,000 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 **9,232** people living with ALS, and more than **\$4,321,817** in grants were provided through our Certified Center Program.

Additionally, educational resources were accessed by over **35,000** people resulting in **27,175** website views, **7,510** downloads, and **557** online orders accessed on Association Care Services website pages. These resources included:

- 12 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
- 13 archived webinars, viewed **2,809** 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 FY2020:

- Supported **73** ALS Association Certified Treatment Centers of Excellence and **22** Recognized Treatment Centers providing multidisciplinary care incorporating best practices as established by the American Academy of Neurology along with **80+** Affiliated Clinic partnerships throughout the US.
- **21,459** people attended support groups offered through our vast U.S. chapter network including people with ALS, caregivers, family members, health care professionals.



HELPING PEOPLE AFFECTED BY ALS CONTINUE THEIR EDUCATION

The ALS Association awarded **\$225,000** to **45 students** from **25 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, vice chair 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



FIGHTING FOR RESEARCH DOLLARS + ACCESS TO HEALTH CARE

During the 2020 fiscal year, The ALS Association's more than 20,000 advocates generated nearly **73,000 messages** to members of Congress. During our annual Advocacy Fly-In and National Advocacy Conference, our advocates completed over 700 meetings with members of Congress.

During the 2020 fiscal year, we increased appropriations for Department of Defense's ALS Research Program from \$10 million to **\$20 million** to find treatments and a cure for ALS.

The ALS Association also enrolled bipartisan congressional champions to reintroduce the ALS Disability Insurance Access Act (S. 578/H.R. 1407) to waive a five-month waiting period for Social Security Disability benefits for people living with ALS. By the end of the 2020 fiscal year, **more than half of each chamber of Congress supported this bill.**





GROWING SUPPORT FOR THE FIGHT

THE WALK TO DEFEAT ALS®

More than **174 walks** were hosted by ALS Association chapters across the country last year, raising **\$26,990,476** to advance our mission to find treatments and a cure for ALS.

TEAM CHALLENGE ALS

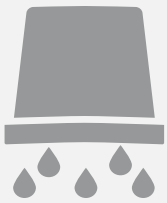
This year the Association's Team Challenge ALS program continued to spread across the country as participants in endurance challenges including marathons, cycling, obstacle courses, and winter sports events came together to combine their passions with a commitment to join the fight. Team Challenge raised **\$5,334,693** with **45 events**.



“IT IS OVERWHELMING TO GO TO THESE WALKS AND SEE HUNDREDS OF THOUSANDS OF PEOPLE THERE TO SUPPORT THE ALS COMMUNITY.”

– Connie Evans from Team Johnnie's Angels
The ALS Association St. Louis Regional Chapter





CELEBRATING FIVE YEARS OF THE ALS ICE BUCKET CHALLENGE

In 2019, with the help of Pete Frates and Pat Quinn, the Association unveiled a new campaign – Challenge Me – to celebrate the fifth anniversary of the Ice Bucket Challenge and to reengage the millions around the world who took part.

Those two words, Challenge Me, allude to the worldwide phenomenon created and shared by ALS patients, their families, and their friends. Just as people living with ALS challenge themselves every day, Challenge Me calls on all of us to have the courage, the strength, and have the courage and conviction to do anything and everything possible to help find a cure for the disease.

Challenge Me is the way anyone and everyone can support people living with ALS. Challenge Me to run faster. Challenge Me to climb higher. Challenge Me to ride farther. Challenge Me to donate. Challenge Me to take part. Challenge Me to advocate. Challenge Me to care more deeply. Challenge Me to fight together.

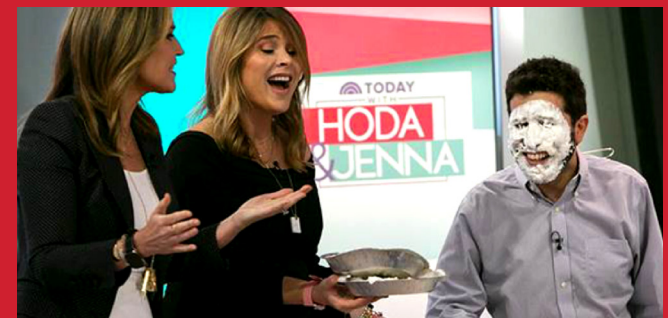
Challenge Me to help find a cure for ALS.

CHALLENGE ME



PIE-IN-YOUR FACE CHALLENGE TAKES OFF

TODAY show hosts Savannah Guthrie and Jenna Bush Hager took part in The ALS Association's **CHALLENGE ME** campaign by taking the pie #InYourFaceALS challenge on air, one of the many ways people participated in the movement. It was an opportunity to spread ALS awareness on social media and to say, "You think I won't take a pie in the face to help end ALS? Challenge Me!"





ALS CORPORATE SPONSORS

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.

QUANTUM REHAB

Quantum Rehab's commitment as a global innovator to improve the quality-of-life needs for people with various functional disabilities has proven invaluable to The ALS Association. Having supported the work of the Association since 2002, Quantum Rehab officially became a national partner in 2012. They have contributed over \$1.9 million to advance the Association's mission through direct cash sponsorships to support national programs, in direct chapter sponsorship support, and in-kind donations of product.



ALS® program, providing support to cutting-edge research, nationwide advocacy efforts, and care service programs for people with ALS and their families. Contributing over \$1.3 million, they continue to support the mission through additional funding for national programs. In addition, they established the Mitsubishi Tanabe Pharma Care Grant since 2018 enabling the Association to award grants for the expansion and implementation of new and current care services programs.

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.



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.



MITSUBISHI TANABE PHARMA AMERICA

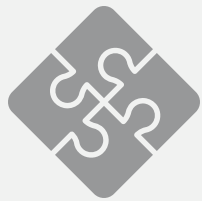
Mitsubishi Tanabe Pharma America became a national corporate partner in 2016 with a premier sponsorship of the Walk to Defeat



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 \$1.4 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.





ALS CORPORATE SPONSORS

POPSOCKETS



PopSockets became a partner to the Association in 2018 donating 10% of online sales of PopSockets grips which help people with mobility issues hold their smartphones more securely. The result to-date has been over \$270,000. Campaign funds go directly to supporting research into treatments and a cure for ALS, ALS advocacy, and care service programs for people living with the disease.

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 \$210,000 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 \$115,500 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 investment of \$300,000 in 2019, the Association is equipped to lean into these two areas further.

GENENTECH



Genentech is a biotechnology corporation that became a subsidiary of Roche in 2009. In 2019, Genentech became a partner of the Association with an investment of \$275,000 helping to support programs such as our National Advocacy Conference and ALS Focus survey program. Both programs support ALS advocacy efforts and understanding how to better serve the ALS community.

VENTEC LIFE SYSTEMS



Ventec Life Systems is redefining respiratory care to improve patient outcomes and reduce caregiver challenges in the hospital and at home. Ventec became a partner of the Association in 2019 with a \$100,000 investment to support educational content to help educate the ALS community and empower them to make decisions that are best for them.



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