



2017 ANNUAL REPORT



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## **VISION:**

Create a world without ALS.

## **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 Leadership

“It has been a tremendous year at The ALS Association. We continued our stewardship of the tremendous support brought to us by the Ice Bucket Challenge and began investing those resources to help bring about our vision of a world without ALS. As you read about what we have accomplished and what we began this past year, do so with our gratitude for the part that you play fighting for people living with ALS.”

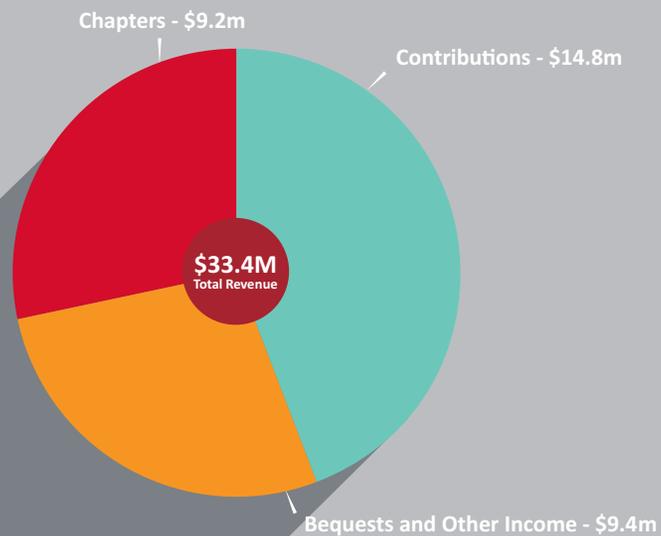
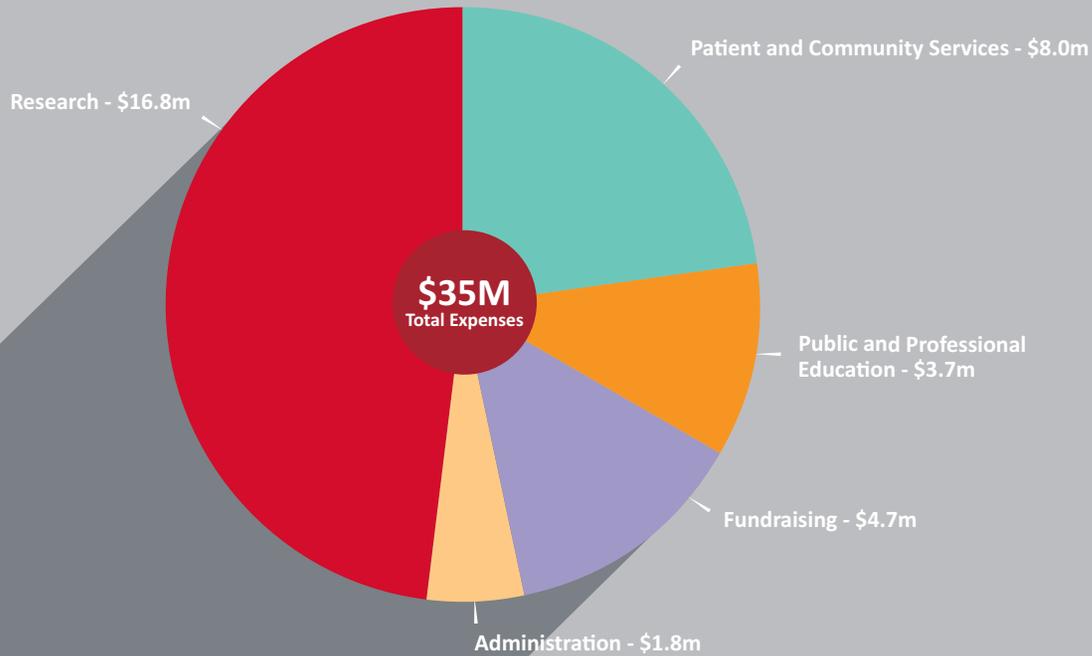
Very best regards,

Barbara J. Newhouse,  
President and CEO

Doug Butcher,  
Chairman, National Board of Trustees



# The ALS Association National Office



## FY2017 Financial Summary

The ALS Association continued to utilize proceeds from the Ice Bucket Challenge to fulfill our mission throughout the fiscal year.

### National Office and Chapters

The following unaudited summary reflects Association-wide financial activity for the year that ended January 31, 2017.

**Total combined revenue - \$83,945,844**

#### Expenses:

Research - \$16,779,742

Other Program Activities - \$50,214,342

Fundraising - \$12,299,996

Administration - \$6,574,117

**Total combined expenses - \$85,868,197**

**Change in net assets - (\$1,922,353)**

**Total combined assets - \$168,228,753**

**Total combined liabilities - \$7,372,897**

**Total combined net assets - \$160,855,856**

# Advancing the search for treatments and a cure

With more than \$19 million committed to support 180 research projects in 11 countries, the ALS Association leaned into its role as a global leader in ALS research during the 2017 fiscal year.

## Major Research Collaborations

The Association announced two new major strategic initiatives this year to advance progress toward finding treatments and a cure: ALS ONE-MAP and NeuroLINCS. These large collaborations are critical to the development of data and resources that can be used by researchers across the world.

Our investments in research collaborations are yielding exciting breakthroughs. With our support, researchers have pushed the ball forward on clinical trials to develop antisense therapy, which prevents the production of proteins targeting two of the most common ALS genes, SOD1 and C9orf72.

## Drug Development

The Association continues to play a leading role by forging partnerships with academic institutions and industry to help drive drug and treatment development. This past year the Association launched the Translational Research Advancing Therapy for ALS (TREAT ALS™) Drug Development Contract grant program, which will fund research to develop new treatments for ALS, and clinical trials we supported moved forward.

## Biomarker Discovery

As part of our commitment to discovering biomarkers, The ALS Association awarded Dr. Timothy Miller and his colleagues at Washington University in St. Louis a \$1 million prize to support their work developing an imaging tracer to track TDP-43 aggregation, which could help researchers understand ALS disease pathways and help track disease progression.

The Association continued its tradition of supporting bright, young scientists in ALS research through the Milton Safenowitz Postdoctoral Fellowship Program. This year, we supported six new postdoctoral fellows. The program falls under our TREAT ALS™ Global Research Program and was founded by the Safenowitz family through the Greater New York Chapter of the Association.



Jeanne McKeon, Ph.D., University of Massachusetts Medical School, 2016 recipient of The Association's Milton Safenowitz Postdoctoral Fellowship.

"I am very grateful for research support from The ALS Association, which will help me determine how ALS-PFN1 causes familial ALS and will yield critical insight into pathogenic mechanisms and druggable targets in the more common form of the disease."

# Caring for people living with ALS

In fiscal year 2017, the Association's chapter network served 14,000 people living with ALS in all 50 states, including 2,000 veterans across the country.

The Association supported 52 Certified Treatment Centers of Excellence and 15 Recognized Treatment Centers, providing multidisciplinary care to people living with ALS, a team approach to care that has been proven to enhance length and quality of life. The Association maintained formal relationships with 63 Affiliated Clinics.

In November 2016, 430 allied health care professionals and clinicians attended the 2016 ALS Association Clinical Conference to discuss new trends, share current practices, exchange ideas and dialogue on challenges and potential solutions in ALS care. The conference also provided continuing education opportunities to professionals representing eight different disciplines working in the ALS disease space.

Care Services continued to engage in community-wide education and awareness, with more than 430,000 visits to the educational resources webpage and 2,625 webinar views or downloads.





# Raising Awareness and Support

## Every Drop Adds Up

In 2016, the Association launched the Every Drop Adds Up Campaign, inspired by the legacy of the Ice Bucket Challenge and the recognition that when people come together, we can make the impossible happen. That is because every challenge, every innovation, every voice, every discovery, every gift ... every drop adds up.

## Team Challenge ALS

This year the Association's Team Challenge ALS program spread across the country as participants in endurance events including marathons, cycling, obstacle courses, and winter sports events came together to combine their passions with a commitment to help.

*“The Ice Bucket Challenge was a game changer. It showed us that when each of us contributes – even just one small act – it adds up and accelerates our pathway toward a treatment for ALS.”*  
– Nancy Frates



## The Walk to Defeat ALS®

More than 175 walks were hosted by ALS Association chapters across the country last year, raising \$25 million to advance the mission to find a treatment and cure for ALS.

# Advocating for Legislative and Policy Priorities

The ALS Association and its nationwide network of 16,000 advocates fought to increase funding for research into treatments and a cure, and for policies that would improve care and access to services for people living with ALS.

## The Association led the fight for

- \$7.5 million in funding for the ALS Registry at the Centers for Disease Control and Prevention. The ALS Registry plays a critical role in connecting people living with ALS to researchers who are dedicated to finding treatments and a cure for this devastating disease.
- \$10 million in funding for the Department of Defense ALS Research. This research is critical because the incidence of ALS in the military is twice that of civilians.
- Congressional action on the ALS Disability Insurance Act, which would eliminate the five-month waiting period for people living with ALS to begin receiving their Social Security Disability Insurance (SSDI) and Medicare after they have been qualified for SSDI. Passage of this legislation is a multi-year effort, and Senate and House bills are still under consideration.



## 21st Century Cures Signed Into Law

The ALS Association, along with other patient advocacy organizations, pushed Congress to pass the 21st Century Cures Act, which was signed into law in December 2016. The law includes many provisions that will improve the discovery, development, and delivery of orphan therapies for rare disease patients, including:

- New FDA funding and regulatory changes to accelerate the drug approval process and facilitate the development of drugs targeting rare diseases.
- Expansion of the Patient-Focused Drug Development Initiative and requirements for the FDA to report on how patient experience data was used in regulatory review.
- Authorization of \$4.8 billion in funds over 10 years for the National Institutes of Health (NIH) to fund the Precision Medicine Initiative, BRAIN Initiative, and the Cancer Moonshot.

# CORPORATIONS MOVE OUR MISSION FORWARD

Thank you to our national partners for supporting our research, care services, and advocacy efforts this year, and for bringing your customers and employees to the fight against ALS.



Quantum Rehab's commitment as a global innovator to improve the quality-of-life needs for people with various kinds of functional disabilities has proven invaluable to The ALS Association. Quantum Rehab is the largest standing national partner of The ALS Association who has contributed to the work of the Association prior to inception of this partnership in 2012. Quantum Rehab has contributed over \$1.6 million to advance the mission of The ALS Association through direct cash sponsorships to support national programs, in direct chapter sponsorship support, and in-kind donations of product.



Permobil has been committed for more than 40 years to helping people with various kinds of functional disabilities. Permobil is the longest standing national partner of The ALS Association. Since the inception of this partnership in 2006, Permobil has contributed nearly \$1.4 million to advance the mission of The ALS Association through direct cash sponsorships to support national programs, in direct chapter sponsorship support, and in-kind donations of product.



Numotion is committed in its leadership as the nation's leading provider of Complex Rehab Technology. Numotion became a national partner of The ALS Association in 2013. Since the inception of this partnership, Numotion has contributed nearly \$1.5 million to advance the mission of The ALS Association through direct cash sponsorships to support national programs, in direct chapter sponsorship support, and in in-kind donations of product. In 2016 alone, Numotion's financial commitment to The ALS Association as a whole was over \$235,000 both in cash and in-kind donations.



MT Pharma America, Inc.

Mitsubishi Tanabe Pharma America became an official national corporate partner of The ALS Association in 2016, with a premier sponsorship of the Walk to Defeat ALS program. This sponsorship provided local support to care service programs, cutting-edge research, and nationwide advocacy efforts for people with ALS and their families. Mitsubishi Tanabe's partnership marked the single largest corporate contribution to date to The Association.



Cytokinetics

Cytokinetics is dedicated to changing the progression of ALS. With few treatment options, Cytokinetics lives this through their work every day to develop a treatment for ALS, while also financially supporting ALS programs, research and care services at the local and national level.

# Our Leadership: The ALS Association Board of Trustees

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